

# **HIV/AIDS IN THE UNITED STATES PACIFIC ISLAND JURISDICTIONS**

A compilation of reports

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Collected by

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## DEFINITIONS OF TERMS

### ASIAN

<b>East Asian</b> <ul style="list-style-type: none"><li>Asian Indian</li><li>Chinese, except Taiwanese</li><li>Taiwanese</li><li>Japanese</li><li>Korean</li></ul>	<b>South Asian</b> <ul style="list-style-type: none"><li>Bangladeshi</li><li>Burmese</li><li>Indian</li><li>Pakistani</li><li>Sri Lankan</li></ul>
<b>Southeast Asian</b> <ul style="list-style-type: none"><li>Burmese</li><li>Cambodian</li><li>Filipino</li><li>Hmong</li><li>Indonesian</li><li>Laotian</li><li>Malaysian</li><li>Mien</li><li>Singaporean</li><li>Thai</li><li>Vietnamese</li></ul>	<b>West Asian</b> <ul style="list-style-type: none"><li>Iranian</li><li>Iraqi</li><li>Lebanese</li><li>Saudi Arabia</li><li>Palestinian</li><li>Syrian</li></ul>

### PACIFIC ISLANDERS

<b>Melanesia</b> <ul style="list-style-type: none"><li>Papua New Guinea</li><li>Solomon Islands</li><li>New Cadelonia</li><li>Vanuatu</li><li>Fiji</li></ul> <b>Micronesia</b> <ul style="list-style-type: none"><li>Palau*</li><li>Northern Mariana Islands*</li><li>Guam*</li><li>Federated States of Micronesia*</li><li>Marshall Islands*</li><li>Nauru</li><li>Kiribati</li></ul>	<b>Polynesia</b> <ul style="list-style-type: none"><li>Tuvalu</li><li>Wallis and Futuna</li><li>Tokelau</li><li>Samoa</li><li>American Samoa*</li><li>Tonga</li><li>Niue</li><li>Cook Islands</li><li>French Polynesia</li><li>Pitcairn</li></ul> <b>Native Hawaiians</b>
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\* 6 United States-affiliated Pacific Island jurisdictions



# Oceania



\*Asterisk indicates the use of child soldiers under the age of 15

Papua New Guinea

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## First PIJAAG Regional Summit on HIV/AIDS / April 24 – 25, 2003 / Participant List

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# First PIJAAG Regional Summit on HIV/AIDS / April 24 – 25, 2003 / Participant List

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## Notes

July 2, 2001

Helene D. Gayle MD, MPH  
Director, National Center for HIV, STD and TB Prevention  
Centers for Disease Control and Prevention  
8 Corporate Boulevard, 6<sup>th</sup> Floor  
Atlanta, GA 30329-2013

Dear Dr. Gayle, MD, MPH,

I am writing as the chair of the Pacific Island Jurisdictions AIDS Action Group (PIJAAG). This letter is to outline some of the barriers faced by communities in the Pacific Island jurisdictions in accomplishing the goals set out by the CDC 5 Year HIV Prevention Strategic Plan. We are requesting a meeting with you at the 2001 National HIV Prevention Conference in Atlanta, August 12-15. We understand you will be transitioning out of CDC at the end of August but hope you will be able to honor our request.

The purpose of this meeting is to discuss the CDC 5 Year HIV Prevention Strategic Plan and the recommendations that PIJAAG has to offer in reaching the Plan's goals. PIJAAG is concerned that the Pacific Island jurisdiction's unique issues and constrained resources will create barriers in the implementation of the plan. Five years from now we hope that the Pacific Island jurisdictions will be on par with the rest of the nation.

Those of us delivering HIV/AIDS prevention services in our respective jurisdictions have become painfully aware that the prevalence of HIV is much greater than originally believed. While the absolute numbers appear small, the impact is great relative to the size of our populations. Currently there are no specific HIV prevention or care services targeting those living on our islands with HIV/AIDS. This not only adds to their suffering but does not give them adequate skills or support to prevent further transmission of HIV. As a part of the United States, it is unconscionable that twenty years into this epidemic our island communities lack a community planning guidance that is appropriate to our HIV prevention needs. Furthermore even the most basic treatment facilities are not available.

PIJAAG congratulates you on your recent appointment as senior advisor for HIV/AIDS with the Bill and Melinda Gates Foundation. PIJAAG wishes you well as you transition out of the CDC and commends you on the body of work established under your leadership and guidance. We gratefully acknowledge your sensitivity to the impact of HIV on people of color communities. As part of this community, we hope to count on your expertise and leadership both now and in the future.

Please contact me to begin discussions on these recommendations and plan our meeting. We look forward to proactively extending our partnership with the CDC to meet the needs of our island communities, and help CDC reach their goals of the 5 Year HIV Prevention Plan of improving nationwide access to HIV services and care.

Sincerely,

Vincent Crisostomo  
Pacific Island Jurisdictions AIDS Action Group Chair

cc:

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## TABLE OF CONTENTS

Attached to this cover sheet are the following:

- I. Table of Contents
- II. Background: Pacific Island Jurisdictions AIDS Action Group
- III. Foreword
- IV. Recommendations
- V. Attachments:
  - A. Overview of issues Regarding HIV and AIDS Cases in the Region
    - Tables: HIV and AIDS cases by Pacific Island Jurisdiction
    - Syphilis and Gonorrhea cases by Pacific Island Jurisdiction
  - B. Current Infrastructure for HIV Service Delivery
    - Table: Matrix of Service Resource Inventory
  - C. Capacity Building
  - D. Background of the Pacific Island Jurisdictions
  - E. Letter of Endorsement by Pacific Island Health Officers Association (PIHOA)



## **HISTORY & BACKGROUND**

### **PACIFIC ISLAND JURISDICTIONS AIDS ACTION GROUP**

In February 2001, representatives from five of the six Pacific Island Jurisdictions (American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam and Republic of Palau) met for five days in Honolulu, Hawai'i to discuss the state of HIV prevention and care services in their respective jurisdictions. This group, which included AIDS directors, program staff, community stakeholders, as well as CDC funded capacity-building assistance providers discussed the shared experiences of the Pacific Island jurisdictions. From these discussions, the group began formulating a regional plan to address HIV/AIDS needs. The group has met three times since that initial meeting; in March 2001 at the *Community Planning Leadership Summit* in Houston, Texas, then in April 2001 at Asian Pacific Islander American Health Forum's *VOICES from the Community Conference* in San Francisco, California and then again in San Francisco in June 2001. At the June 2001 meeting the Republic of the Marshall Islands joined Pacific Island Jurisdictions AIDS Action Group (PIJAAG) for the first time.

As a result of these meetings, the Pacific Island Jurisdictions AIDS Action Group formed and created this mission statement to advance this regional approach.

### **PIJAAG MISSION STATEMENT**

We are representatives of the United States affiliated Pacific Island Jurisdictions standing united to speak in one voice around the shared issues of HIV/AIDS in our island communities.

- § We advocate for the provision of quality HIV prevention and care services in the region.
- § We advise national, international, and local policy entities on HIV/AIDS.
- § We strengthen and coordinate AIDS activities through the sharing of information and resources within the region.

PIJAAG strongly advocates for changes in the response to the AIDS epidemic in the Pacific region, both internally as a region and externally from federal agencies like the Centers for Disease Control & Prevention (CDC) and Health Resources and Services Administration (HRSA). PIJAAG sees the need to develop a regional model of HIV prevention and services.

### **PIJAAG JURISDICTION REPRESENTATIVES**

*American Samoa:* Fara Utu

*Commonwealth of the Northern Mariana Islands:* David Rosario

*Federated States of Micronesia:* Louisa Helgenberger

*Guam:* Josie O'Mallan and Vincent Crisostomo

*Republic of the Marshall Islands:* Dr. K. Briand and Jonathan Santos

*Republic of Palau:* Johana Ngiruchelbad



## PIJAAG ACTIVITIES AS OF JULY 2001

- 1 **Health Resource and Services Administration (HRSA):** Since February 2001, PIJAAG has met three times with Health Resources and Services Administration (HRSA) representatives, both with HIV/AIDS Bureau and Region IX staff to discuss developing and strengthening HIV care services in the jurisdictions from local as well as regional perspectives. From these meetings, the Pacific Islander jurisdictions strategized their submissions for Title II funds (five for the first time); and all were successful in their applications. Finally, from these meetings a collaborative regional Title III grant was developed, working in conjunction with each jurisdiction's Title II award and Title III planning grant applications. This is a first step in realizing PIJAAG's vision of a regional approach to the HIV epidemic.
- 1 **National Alliance of State and Territorial AIDS Directors (NASTAD):** PIJAAG has also been instrumental in the advocacy for Pacific Island jurisdictions with two PIJAAG members attending the April NASTAD annual AIDS directors meeting to advocate for a greater NASTAD role in the Pacific.
- 1 **Pacific Island Health Officers Association (PIHOA):** PIJAAG has been successful in advocating for PIJAAG support (see attached PIHOA letter of support). PIHOA is the association of Health Ministers and Department of Health directors in the Pacific. Through PIJAAG members' urging, PIHOA made HIV/AIDS in the Pacific the focus of their Spring 2002 meeting, with a scheduled presentation by PIJAAG.
- 1 **Inter-island Collaboration:** PIJAAG supports the increase of collaboration between the jurisdictions by sharing information and resources. A case conferencing session on migrating clients in the region took place at their April meeting. In this session, the Pacific Island jurisdictions had an opportunity to discuss strategies on specific cases that pertained to multiple jurisdictions, given the migration of clients. Issues of confidentiality, policies and procedures, and the uneven availability of services were discussed. The discussion also brought forward provocative approaches to address these issues, such as a shared medical records system and regional case management, as well as continuing case conferencing so a person living with HIV/AIDS's (PLWHA) experience accessing services is easier and more efficient throughout the region.

## FOREWORD

PIJAAG feels strongly that twenty years into the epidemic with no relief in sight, several changes need to be made to respond to the AIDS epidemic in the Pacific region. The release in January 2001 of the CDC 5 Year HIV Prevention Strategic Plan made no specific mention of the Pacific Island jurisdictions. The plan as written can only be implemented and realized if thought and resources are allocated now. As a result, PIJAAG has developed seven recommendations which are being respectfully submitted to the Centers for Disease Control and Prevention for consideration and further discussion.

The seven recommendations that follow are made in the spirit of the interim report of the President's Advisory Commission on Asian Americans and Pacific Islanders, *A People Looking Forward: Action for Access and Partnerships in the 21st Century*. PIJAAG wishes to emphasize that our requests to the CDC are done in the spirit of collaboration and partnership, with a shared sense of urgency in the goal of improving healthcare with respect to HIV/AIDS in the Pacific Island jurisdictions. PIJAAG is committed to and advocates for actions to improve access and enhance partnerships with the CDC that will ensure the successful implementation of the CDC 5 Year HIV Prevention Strategic Plan.

**PACIFIC ISLAND JURISDICTIONS AIDS ACTION GROUP  
RECOMMENDATIONS  
TO THE CENTERS FOR DISEASE CONTROL AND PREVENTION**

**RECOMMENDATIONS FOR IMPLEMENTATION OF THE CDC 5 YEAR HIV  
PREVENTION STRATEGIC PLAN**

*"Data collection, research efforts, preventive measures and a suitable health care infrastructure need to be developed to address the particular health problems and disparities faced by Pacific Islanders."*

- Interim report of the President's Advisory Commission on Asian Americans and Pacific Islanders, *A People Looking Forward: Action for Access and Partnerships in the 21st Century*, p.87.

**1. RECOMMENDATION:**

**CDC should clarify how the Pacific Island jurisdictions fit into the CDC 5 Year HIV Prevention Strategic Plan through 2005.**

**RATIONALE:**

It is unclear how the following goals in CDC's 5 Year HIV Prevention Strategic Plan can be implemented in the Pacific Island jurisdictions:

- (1) *Goal Three:* increase from the current estimated 50% to 80%, the proportion of HIV-infected people in the United States who are linked to appropriate prevention, care and treatment services; and
- (2) *Goal Four:* strengthen the capacity nationwide to monitor the epidemic, develop and implement effective HIV prevention interventions and evaluate prevention programs.

As of July 2001 these services targeting HIV-infected people either do not exist or are extremely limited in the Pacific Island jurisdictions. Lack of resources in the jurisdictions make reaching these two objectives especially challenging given the current gaps in HIV surveillance, prevention and care services. We would appreciate clarification from CDC on how the strategic plan applies to the Pacific Island jurisdictions and what resources CDC will commit to ensuring that the goals and objectives of the CDC 5 Year HIV Prevention Strategic Plan will be met in the Pacific by 2005 (Please Attachment A., "HIV Treatment and Support Services").

- (3) *Goal Five:* assist in reducing HIV transmission and improving HIV/AIDS care and support in partnership with resource constrained countries.

This goal is admirable but once again the Pacific Island jurisdictions need to ask "*What about us?*" The Pacific Island Jurisdictions are both "*nationwide*" and "*international*" as well as "*resource constrained*", yet what considerations have been given to the region?

At a February 2001 meeting attended by PIJAAG, a presentation was done by a CDC Project Officer on the CDC 5 Year HIV Prevention Strategic Plan. Questions to the presenter on the applicability to the Pacific Island jurisdictions were met with defensiveness and their responses were generally unsatisfactory. CDC staff, when presenting on its 5 Year HIV Prevention Strategic Plan or any other nationwide effort sponsored or initiated by CDC, should at the very



minimum be able to address questions raised by the Pacific Island jurisdictions respectfully and with something other than, "I'm not the project officer for that region." A similar response happened in Atlanta at the U.S. Conference on AIDS in October 2000 during a question and feedback session. A 'nationwide' plan must include the Pacific Island jurisdictions; furthermore, this plan should address the unique HIV prevention needs of this region.

**REQUEST:**

- a. Official written clarification on how the Objectives of the CDC 5 Year HIV Prevention Strategic Plan will be implemented and supported in the Pacific Island Jurisdictions.
- b. Establishment of a baseline of knowledge and training for CDC staff on what constitutes 'nationwide'.

**2. RECOMMENDATION:**

**CDC should assist the Pacific Island jurisdictions in ensuring that federally approved standards of quality care and practice are implemented.**

**RATIONALE:**

During the February 2001 meeting with representatives from 5 of the 6 U.S. affiliated Pacific Island jurisdictions, a simple resource inventory of each Pacific Island jurisdiction's strengths and challenges in testing, prevention programming and care services was conducted. Through this exercise, it was clear that there is a large gap between what currently exists in the Pacific Island jurisdictions and the federally approved standards for testing, prevention and care services. As United States territories and freely associated states, but moreover as human beings, our communities have a right to receive quality and comprehensive care that is delivered at industry standards or better. The members of our communities should not have to travel long distances and incur great expense for the most basic of HIV services. In order to implement and meet the objectives of the CDC 5 Year HIV Prevention Strategic Plan the federally approved standards of quality care and practice must be implemented.

**Examples:**

- ξ Currently, confirmatory Western Blot testing cannot be done in any of the 6 Pacific Island jurisdictions. Samples requiring confirmatory HIV antibody testing are sent to Hawai'i or Australia. However, the airline serving the Pacific to Hawai'i refuses to transport "infectious agents", i.e. blood samples for confirmatory tests. In addition, the confirmatory tests are expensive and can take up to 6 weeks to process (Please see Attachment A., "Lack of HIV Service Infrastructure")
- ξ While some states in the Federated States of Micronesia are providing HIV antibody testing, there is no current capacity to provide pre-test or post-test HIV counseling in all cases, a critical component of all HIV prevention strategies.
- ξ The Federated States of Micronesia and American Samoa have inadequate resources to fully screen the blood supply.

**REQUEST:**

- a. Establish a team of experts (CDC project officers, capacity building assistance providers, regional service providers, etc.) to conduct onsite visits to assess and

support the Pacific Island jurisdictions in delivering federally approved standards of quality care and practice.

- b. CDC needs to commit its support and funds to ensure that a baseline level of HIV prevention services and linkage to care services are provided in the Pacific Island jurisdictions. This will ensure the implementation of the CDC 5 Year HIV Prevention Strategic Plan's goals.

### **RECOMMENDATIONS FOR COORDINATED PROJECT MANAGEMENT BY CDC AND OTHER FEDERAL AGENCIES**

#### **3. RECOMMENDATION:**

**Inter-agency coordination of CDC's agencies and programs should be improved in the Pacific.**

##### **RATIONALE:**

The Pacific Island jurisdictions have integrated STD/HIV departments that are oftentimes managed by the same person. Closer contact and communication between the project officers for HIV and STD divisions would lead to improved coordination. This will become even more critical when linking those living with HIV infection to treatment and support.

##### **REQUEST:**

- a. CDC programs should coordinate efforts with other agencies in the Department of Health and Human Services (HHS). In addition, the CDC should conduct at least one annual face-to-face meeting that is attended by representatives from the Pacific Island jurisdictions, CDC programs and HHS agencies that service the Pacific.
- b. CDC should advocate for and participate in the creation of an inter-HHS-agency group for Pacific Islander affairs. This would be useful for coordination and maximizing our efforts and limited resources. One or two people in each jurisdiction are often coordinating with several different CDC programs (HIV, DASH, Hepatitis B, TB), as well as other HHS agencies (HRSA, SAMHSA). The Department of Interior has set this example by convening the Inter-agency Group on Insular Affairs (IGIA).

#### **4. RECOMMENDATION:**

**CDC should ensure an annual visit by the assigned Project Officer.**

##### **RATIONALE:**

CDC project officers assigned to the Pacific Island jurisdictions have historically shown little or no interest in the region. The current project officer, Vicky Rayle, is a welcome exception. However, her work has been hampered by the fact that she has not yet visited the region. It is our understanding that project officers are required to visit their projects at least once per year, yet it seems that the Pacific Island jurisdictions are an exception to that.

Federal agencies need to increase their knowledge and understanding of Pacific Islander histories, cultures and issues. As well, Pacific Islanders need to know and understand the CDC and other government agencies. Many of us travel to conferences more than once a year that are far from our loved ones and in very different climates, which often do not even address our issues or concerns. Information becomes difficult to absorb after the lengthy travel and time changes - yet year after year we comply. It is only fair that our project officer be allowed to travel to the Pacific Island jurisdictions to better understand what we face on a day-to-day basis. Finally, no report or application can sufficiently convey the conditions of the Pacific like an onsite visit can.

**REQUEST:**

- a. Onsite visit by assigned Project Officer at least once a year. This can be scheduled on an annual or timely basis, but it needs to happen.

**RECOMMENDATIONS ON HIV PREVENTION PLANNING**

*"The time and resources that must be devoted to preparing these applications and establishing and maintaining the programmatic infrastructure required under these grants is often not proportional to the levels of federal funding received."*

- Interim report of the President's Advisory Commission on Asian Americans and Pacific Islanders, *A People Looking Forward: Action for Access and Partnerships in the 21st Century*, p.88

**5. RECOMMENDATION:**

**CDC should provide additional assistance to the Pacific Island jurisdictions in developing a modified community planning guidance as well as support regional planning.**

**RATIONALE:**

The Community Planning Groups that exists in each jurisdiction will be critical in coming up with plans to meet the objectives of the CDC 5 Year HIV Prevention Strategic Plan, yet the community planning process is built on the assumption that there are community-based organizations (CBOs) available to implement the Plan. However, with the exception of Guam, there are no CBOs or Non-Governmental Organizations (NGOs) capable of delivering services in the Pacific Island jurisdictions. The health department is often not the most appropriate provider of certain HIV services due to perceived issues of confidentiality and fear of stigma. This creates a barrier to the implementation of the community prevention plan. In fact, the roles of planning and implementation - separate in the 50 states - are conflated in the Pacific Island jurisdictions. PIJAAG advocates for the development of a prevention planning process that takes into account the resources and capacity required to implement such a plan. PIJAAG recommends the integration of prevention and care planning. Finally, the Pacific Island jurisdictions would benefit from the establishment of an HIV service planning process that involves a coordinated effort of all six Pacific Island jurisdictions working together to create a regional response to HIV/AIDS (Please see Attachment B, "Overall Health Services Delivery in the Pacific Island Jurisdictions" and "HIV Service Delivery Infrastructure").



#### **REQUEST:**

- a. CDC should support the creation of an appropriate HIV Community Planning guidance for the Pacific Island jurisdiction.
  - One strategy is the creation of a separate application process specifically for the Pacific Island Jurisdictions.
  - Another is to supplement current Community Planning budgets to enhance each jurisdiction's capacity to participate in a coordinated effort.
  - A third strategy is the creation of a regional Community Planning process involving all 6 Pacific Island Jurisdictions.

#### **RECOMMENDATIONS FOR A COORDINATED APPROACH FOR CAPACITY BUILDING ASSISTANCE**

*Capacity-building and funding of Asian American and Pacific Islander communities that serve smaller, more geographically isolated or emerging populations are needed. Government funders have little knowledge of these communities and the emerging organizations in those communities have little knowledge of the funding opportunities available.*

- Interim report of the President's Advisory Commission on Asian Americans and Pacific Islanders, *A People Looking Forward: Action for Access and Partnerships in the 21st Century*, p.75.

*If you have come to help me, then you can go home again. But if you see my struggle as part of your own survival, then perhaps we can work together.* - Australian Aborigine woman

#### **6. RECOMMENDATION:**

**CDC should involve the Pacific Island Jurisdictions in the selection of capacity building assistance providers for the Pacific region.**

#### **RATIONALE:**

Trainings offered by capacity building assistance providers should be geared to meet the needs of the Pacific Island jurisdictions. Furthermore, the inter-departmental coordination of project officers will maximize effective and efficient capacity building assistance activities for the region. More often than not the Pacific Island jurisdictions needs are not adequately assessed due to the expense, differing time zones, general lack of knowledge. Most importantly because we are rarely consulted about our capacity building assistance needs. This leads to a breakdown in communication and once on-site these so called 'experts' have been known to be culturally insensitive to program personnel working in the Pacific. When an actual need arises we are told "we have already done a training there" and "there is no need for further CBA provision". CBA providers should adhere to a client-centered model. The Pacific Island jurisdictions must be involved in determining their CBA needs as well as the selection of the most appropriate CBA providers (Please see Attachment C).

The Pacific Island jurisdictions and PIJAAG have long-standing and productive relationships with Asian and Pacific Islander American Health Forum (APIAHF). APIAHF has proven itself to be culturally sensitive and competent in addressing our needs. For the last few years the Pacific Island jurisdictions have worked with APIAHF to build a plan for technical assistance

and training that is both relevant and strategic. The Pacific Island Jurisdictions AIDS Action Group (PIJAAG) is a direct result of this ongoing collaboration. CBA providers would be more effective in leveraging resources if they worked in collaboration with APIAHF (Please see Attachment C).

The knowledge gained by the sharing of experiences and strategies was profound at the founding meeting of PIJAAG. When traveling to conferences on the continental U.S., the HIV/AIDS issues facing the Pacific Island jurisdictions are often lost. CDC should support and provide for more training opportunities in the Pacific on a regular basis - at the very minimum on an annual basis.

**REQUEST:**

- a. PIJAAG respectfully requests that CDC ensure that all capacity building assistance offered to the region be coordinated in collaboration with the Asian and Pacific Islander American Health Forum (APIAHF) of San Francisco.
- b. CDC should fund a yearly CBA meeting for the Pacific located in one of the Pacific Island jurisdictions.

**7. RECOMMENDATION:**

**CDC should consider funding Guam as a technology and information transfer point for the Pacific region, and establish a direct relationship with Guam.**

**RATIONALE:**

As of March 1, 2001, among the 6 Pacific Island Jurisdictions, Guam has seen 142 cases of HIV infection and AIDS diagnoses on the island. Last year the Guam Community Planning Group (CPG) surveyed 50 persons living with HIV for their input into the HIV Prevention Plan. Given the high rates of HIV infection relative to the population and given the increased level of inter-island travel in the Pacific, especially with Guam as a hub, PIJAAG feels that CDC should consider supporting a regional approach to HIV prevention and pay special attention to Guam's role in this epidemic. The other Pacific Island jurisdiction's Health Departments as well as residents of those islands are already turning to both Guam's Department of Public Health and the community based organization, Coral Life Foundation, to provide not only services but technical assistance and support.

As a technology and information transfer point, Guam could consolidate the CBA that is available in the Pacific and be welcomed partners with the Asian & Pacific Islander American Health Forum (APIAHF) to further collaborate with other organizations outside the Pacific who do capacity building. More importantly, this partnership could formalize existing networks and begin to tackle our long-term capacity building needs such as the implementation of the CDC 5 Year HIV Prevention Strategic Plan, development of non-governmental organizations, and regional data gathering and planning.

**REQUEST:**

- a. CDC should begin to access Guam's role in collaboration with other regional and national CBA efforts, and designate resources to formalize Guam as a technology and information transfer point for the Pacific region.



## **CLOSING**

PIJAAG realizes that we cannot achieve our goals alone. We thank the CDC (and its funded CBA providers) for their support of our efforts in this area so far. PIJAAG extends it's partnership in order to ensure the successful implementation of the CDC 5 Year HIV Prevention Strategic Plan. We look forward to working together to create solutions and build momentum to bring about significant change in the delivery of HIV prevention and care services. With CDC's support and commitment, we can do this together with mutual support and commitment.

## OVERVIEW OF THE ISSUES REGARDING HIV AND AIDS CASES IN THE REGION

The Pacific Island jurisdictions have several factors that emphasize the need for a comprehensive continuum of HIV prevention and care services in each jurisdiction and coordinated HIV services in the region. The following statistics are gathered through the face-to-face meetings of Pacific Islander Jurisdictions AIDS Action Group (PIJAAG). This information has also been included in support of the regional model submitted by PIJAAG and Asian and Pacific Islander American Health Forum (APIAHF) in their June 2001 Capacity Building Title III proposal to HRSA.

### 1) HIV STATISTICS

#### A. HIV Surveillance Issues

There are discrepancies between the numbers of HIV/AIDS cases known to the Pacific Island jurisdictions themselves versus the CDC surveillance reports. The following HIV and AIDS cases come from the jurisdictions themselves, not the CDC. The official CDC surveillance reports through December 2000 had only 46 cumulative AIDS cases in the region of the Pacific Island jurisdictions. At the August 1999 Counseling Testing Referral Partner Notification Conference of the Jurisdictions, CDC discovered that HIV cases reported from the jurisdictions had not reached the CDC. CDC is currently investigating these discrepancies. In the meantime, the Jurisdictions have reported their updated CDC applications for base-line funding as well as their HRSA Title II applications. These on-going issues further highlight the need for prioritized attention.

#### B. Overall Population

These population estimates show the small population size of the jurisdictions. This population size as well as the geographically isolated nature of the island community's needs to be taken into account to understand the impact of HIV. Additionally to reflect the population sizes, rates when given are calculated per 1,000 instead of 100,000.

American Samoa: 65,446 (CIA 2000 estimate)

CNMI: 79,429 (Department of Commerce/Division of Statistics)

FSM: 133,144 (CIA 2000 estimates)

Guam: 154,623 (CIA 2000 estimates)

RMI: 68,126 (CIA 2000 estimates)

Republic of Palau: 19,129 (Republic of Palau 2000 census)

#### C. Number of Known AIDS Cases

JURISDICTION	NEW AIDS CASES 1998	NEW AIDS CASES 1999	NEW AIDS CASES 2000	AIDS cumulative (1985-2000)
American Samoa	0	0	0	0
Commonwealth of the Northern Mariana Islands	2	1	1	16
Federated States of Micronesia	1	0	1	4
Guam	8	8	7	59
Republic of the Marshall Islands	0	0	0	2
Republic of Palau	0	1	0	2
<b>TOTAL FOR REGION</b>	<b>11</b>	<b>10</b>	<b>9</b>	<b>83</b>

## D. HIV Numbers and Rates

JURISDICTION	HIV Known in area	HIV <i>Cumulative reported</i>	Current HIV projections as of 2000
American Samoa	1 or 0.01/1,000	1	Not available
Commonwealth of the Northern Mariana Islands	10 or 0.13/1,000	38	320 or 4.03/1,000
Federated States of Micronesia	8 or 0.06/1,000	11	90 or 0.68/1,000
Guam	77 or 0.50/1,000	131	450 or 2.91/1,000
Republic of the Marshall Islands	Not available	9	Not available
Republic of Palau	2 or 0.10/1,000	2	No official projections
<b>TOTAL FOR REGION</b>	<b>98+</b>	<b>192</b>	<b>860+</b>

Sources: DPH / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau. Additional information from PAETC 2000 Report, OIA 1999 Report, OIA Fact Sheets, CIA World Factbook 2000, AusAIDS Strategic Plan, and Title II Applications / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau

## E. Communities at Risk

## i. Modes of Transmission

The sub populations at highest risk for HIV/AIDS vary in each jurisdiction. In Guam, for example, Men having Sex with Men (MSM) continue to be the group at highest risk for HIV/AIDS, comprising 70% of HIV cases and 63% of AIDS cases in 1999. Both injecting drug users and heterosexual men and women accounted for 10% of new HIV cases (*Guam Title II application*). While historically MSM were the highest risk group in CNMI, the epidemiology has been changing to include women, teenagers, and newborn babies. Cumulatively, heterosexual men comprise 29% and heterosexual women comprise 29% of the HIV cases in CNMI (*CNMI Title II application*). Most of FSM's HIV/AIDS cases are among the male population (*FSM Title II application*). In CNMI, foreign workers must submit to health screenings including HIV testing. Between 1998 and 1999, 6 cases have been reported among workers from the Philippines (0.46/1,000), 4 cases among workers from China (0.27/1,000), and 5 cases among workers from Thailand (8.43/1,000) (*CNMI Title II application*).

## ii. Racial/Ethnic Communities At Risk

HIV/AIDS cases in the jurisdictions are primarily in Pacific Islander and Asian populations. 1999 AIDS cases in Guam shows that 72% of the cases are Pacific Islander or Asian; this population also accounts for 60% of HIV cases that year. In 2000, Guam's seven new cases include five Chamorro/Guamanian and two FSM citizens. CNMI's cumulative HIV/AIDS cases through 2000 indicates that 95% of PLWHA are Pacific Islanders or Asians.

## F. Additional Issues for HIV/AIDS Surveillance

## i. Migrant Community

The numbers of HIV reported cases do not show the true number of cases in the Jurisdictions and the extent of HIV service burden on the jurisdictions. People may test HIV positive off island but later return home for services. This may be especially true for Pacific Islanders, where cultural and

linguistic as well as familial ties bring many People Living With HIV/AIDS (PLWHA) home when they become sick and require care (*Pacific AIDS Education & Training Report 2000*). For example, in American Samoa, six PLWHA, not tested in the islands, came to American Samoa with end-stage AIDS (*PAETC report 2000*). However, this is not reported as AIDS cases in American Samoa and officially, the island has “zero” AIDS cases. The HIV projections may be a more accurate way to describe the potential burden of care each jurisdiction will face.

Pacific Islanders may also be testing elsewhere because of the lack of confidentiality available for HIV testing. “In most jurisdictions, despite some efforts to the contrary, there is little protection of patient’s confidentiality and everyone knows who is being treated for any disease – including HIV...” (*PAETC Report 2000*).

### iii. Lack of HIV Service Infrastructure

Lack of HIV testing capacity also may deter people from testing in the jurisdictions. If HIV testing is available, it can take 4-6 weeks to get test confirmatory results in some jurisdictions, because lab work must be sent off island, usually to Hawai’i or Australia (*PIJAAG February meeting*).

Pacific Islanders may test off island because of the lack of HIV care services in the jurisdictions. Five of the six jurisdictions are receiving Title II funds for the first time this year. Even Guam, with the most developed HIV service delivery system in the region, has no case management and “...does not have a continuum of HIV care services” (*Guam Title II application*). Without services available, there is little incentive to test.

## 2) RATES OF SEXUALLY TRANSMITTED DISEASES

### A. Syphilis and Gonorrhea Rates

JURISDICTION	Syphilis 1998	Syphilis 1999	Gonorrhea 1998	Gonorrhea 1999
American Samoa	2 or 0.03/1,000	5 or 0.08/1,000	13 or 0.20/1,000	16 or 0.24/1,000
Commonwealth of the Northern Mariana Islands	214 or 2.69/1,000	97 or 1.22/1,000	41 or 0.52/1,000	29 or 0.37/1,000
Federated States of Micronesia	Not available	Not available	180 or 1.35/1,000	238 or 1.79/1,000
Guam	7 or 0.05/1,000	9 or 0.06/1,000	73 or 0.47/1,000	55 or 0.36/1,000
Republic of the Marshall Islands	91 or 1.34/1,000	72 or 1.06/1,000	26 or 0.38/1,000	88 or 1.29/1,000
Republic of Palau	16 or 0.84/1,000	18 or 0.94/1,000	115 or 6.01/1,000	36 or 1.88/1,000
<b>TOTAL FOR REGION</b>	<b>330+</b>	<b>201+</b>	<b>448</b>	<b>462</b>

Sources: DPH / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau. Additional information from PAETC 2000 Report, OIA 1999 Report, OIA Fact Sheets, CIA World Factbook 2000, AusAIDS Strategic Plan, and Title II Applications / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau



These high rates of STDs imply a sexually active population and can be used as a surrogate marker for HIV infections. For example, gonorrhea rates are extremely high in the Republic of Palau; its 1999 rate (1.88/1,000) is higher than the U.S. population rates for whites (0.28/1,000), Hispanics (0.75/1,000), American Indians/Alaska Natives (1.11/1,000) and Asians & Pacific Islanders overall (0.22/1,000). This is also true for the 1999 rates of gonorrhea in FSM (1.79/1,000) and RMI (1.29/1,000). All jurisdiction's STD rates are higher than the overall rates for Asians & Pacific Islanders and whites. The 1999 syphilis rates in CNMI (1.22/1,000) and RMI (1.06/1,000) are similarly high, compared to the rate for the total population in the U.S. (0.03/1,000) (*Tracking the Hidden Epidemics 2000: Trends in STDs in the United States / CDC*).

Other STD rates, such as Chlamydia, are also extremely high in some of the jurisdictions: RMI (0.54/1,000), Guam (0.30/1,000), and Palau (0.31/1,000). Furthermore, Guam's Chlamydia incidences rates by ethnicity showed Chuukese and others of FSM ancestry had the highest incidence.

These rates imply sexually active populations with unprotected sex and multiple sexual partners. These conclusions are consistent with the 1997 Youth Risk Behavior Survey (CNMI), where 57% of students surveyed have had sex by the 12<sup>th</sup> grade and 80% of sexually active teenagers surveyed don't use any contraception. Anecdotal information from Coral Life Foundation states that in a recent syphilis outbreak this year, 4 of the men were also PLWHA, further suggesting the possibility of HIV transmission. Through focus groups conducted in 2000 by the HIV Prevention Program in Palau, a comprehensive STD/HIV/AIDS needs assessment found that multiple partners and extra-marital sexual relations remain very common among men. The assessment also found that many Palauan men are customers of local commercial sex workers and that safe sex is far from universal within this industry (*Palau Title II application*).

## CURRENT INFRASTRUCTURE FOR HIV SERVICE DELIVERY

### 1) OVERALL HEALTH SERVICE DELIVERY

Health care delivery in the region comes under the Department or Ministry of Health and is divided between the hospital services and the public health departments. There are few non-governmental agencies (in all areas of health and social services, including HIV/AIDS). All the jurisdictions rely on the strengths of their health departments, hospitals, and Ministries of Health for the majority of their health care and social service needs.

### 2) HIV SERVICE DELIVERY INFRASTRUCTURE

HIV Services, including prevention and care, are provided mainly through the public health departments. While there are some private providers that see PLWHA in Guam and CNMI, most of the jurisdictions do not have this luxury. In all of the jurisdictions, the health departments play a key role in the provision on HIV services. However these programs have only a handful of staff, with HIV programs usually combined with STD programs. The only AIDS service organization in the region, Coral Life Foundation, has only two staff. Founded in 1993, Coral Life Foundation was the first non-governmental organization based in the Pacific Island region to receive federal funds for HIV prevention in 1999.

### 3) MATRIX OF SERVICE RESOURCE INVENTORY

JURISDICTION	Outreach	Pre-test Counseling	Testing	Post-test Counseling	Partner Notification	Individual Level Interventions	Group Level Interventions	Community Level Interventions	Media	Referrals	Primary Care	Outreach to PLWA	Early Intervention Services	Medication Availability	Case Management	CD4 Count	AETC
CNMI	X	X	X	X	X	X	X	X	X					*4			
FSM-Pohnpei	X						X	X	X					*4			X
FSM-Chuuk	X		X *3		X	X	X	X	X	X				*4			
FSM-Yap	X						X	X	X					*4			
FSM-Kosrae	X													*4			X
Guam	X	X	X	X	X	X	X	X	X	X	X			X		X	
Palau	X	X	X	X	X	X *2	X	X	X					*4			
RMI	X	X	X	X	X	X	X	X	X	X				*4			
American Samoa	X	X	X	X	X	X *1	X	X	X			X		*4			X

Prevention -----! Care

\*1 Needle Sticks

\*2 No Curriculum

\*3 Clinic

\*4 Not Routinely Available

Information collected at the April 2001 PIJAAG meeting. Additional information was gathered from HIV prevention applications.

Though an initial reading may indicate that a fair amount of HIV services (specifically prevention) is currently being provided further investigation is needed to understand the full scope of the situation in the region. While all jurisdictions are providing HIV prevention interventions to their local populations, the availability of interventions and their thoroughness vary.

#### A. HIV Testing

Federated States of Micronesia (FSM) is providing HIV antibody testing (in Chuuk), but doesn't have the current capacity to provide pre- and post- test counseling, a critical component of all HIV prevention strategies. Also, testing in FSM is not available in every state and is inaccessible because of transportation, time, and cost to travel inter-island. Testing itself has been an issue, as lab work needs to be sent off island to Hawai'i or Australia; FSM and Palau currently are having problems with the only air carrier for the region, Continental Micronesia, which refuses to transport "infectious agents", even if the specimens are properly packaged. Other problems include the time it takes for the test results to be returned; in American Samoa, there are only two flights a week (Mondays and Fridays) and confirmatory tests may take 4-6 weeks to be returned. In at least one instance, results took 2 months (*PIJAAG April meeting*). For all the jurisdictions, Western Blot confirmatory tests must be sent to Hawai'i or Australia.

Furthermore this also endangers the blood supply of some of the jurisdictions, with both FSM and American Samoa currently not screening donated blood (*PAETC 2000 Report and PIJAAG February meeting*). This is due to the lack of equipment and staff training to test the supply.

#### B. HIV Treatment and Support Services

##### Guam

Only Guam currently is the only jurisdictions offering limited HIV-specific primary care services to PLWHA. Guam is able to provide CD4 counts and viral load testing; other jurisdictions cannot. Guam also has funds for drug therapies; the other jurisdictions do not. However, Guam is limited in its resources and cannot offer early intervention or case management services. With this gap, Guam is not able to provide client-centered services to link individuals with primary health care, psycho-social and other services in a timely manner; provide on-going assessment of the client's needs, and development of a service plan. Guam's health department does work closely with the only AIDS service organization in the region, Coral Life Foundation, to provide some limited HIV care services (through foundation money) and HIV prevention, but the resources are minimal.

##### CNMI

CNMI has some of the infrastructure to provide primary health services to PLWHA, though not specifically HIV primary care. There is some coordination plans with other federal services as well as linkages with prevention and substance use programs. Recently, the HIV/STD Program has been given a government building that will be converted into a center for PLWHA support activities.

##### Palau

Care services in Republic of Palau are also in the early stages of development. There are no specific HIV care services currently in place. With 2 new cases in 2000 and 2001, Palau is facing difficult situations because of the lack of HIV care service infrastructure. Medications have been initiated to prevent prenatal transmission for an HIV positive pregnant woman; however, the treatment was initiated without baseline CD4 counts and viral load testing, currently unavailable in Palau. Her blood specimens could not be transported off-island for needed tests as the samples once deemed infected aren't accepted for transportation by the only airline carrier in the region. Medication for this woman had to be borrowed from another jurisdiction. Provision for future treatment of her and other PLWHAs in Palau is still not clear (*Palau Title II application*).

American Samoa, RMI and FSM

There are no currently no HIV care services in these jurisdictions but are they are in the process of developing them. Both RMI and FSM do not have funds for medication (and are ineligible for Medicaid programs). Currently in FSM, the only treatments available to PLWHA are antibiotics and intravenous fluids (*PIJ AAG April meeting, FSM Title II application*).



## **CAPACITY BUILDING**

### **1) CAPACITY BUILDING NEEDS**

It is recognized that all jurisdiction's provide primary care to people in need of services, including PLWHA, through their public health care systems. These systems alone are not equipped with the complexity and specialization needed to adequately provide HIV care to PLWHA. Only Guam currently has the capacity to provide some HIV-specific primary care services. The need for capacity building assistance in the jurisdictions is real and apparent.

The Guam Conference Report from the University of Hawai'i on its recent HIV/AIDS conference (January 2001) for physicians, nurses, and other health care professionals in the Pacific Island region identified five areas of need for the management of HIV in the jurisdictions.

- 1) Communication between the jurisdictions needs to be improved, including the sharing of information about migrating PLWHA throughout the region.
- 2) Communication and support within each jurisdiction is needed to coordinate HIV care services.
- 3) The jurisdiction needs to have access to information from outside the region.
- 4) Training for health care providers and the community-at-large on the continuum of HIV related issues and community mobilization strategies are needed.
- 5) Funding for programs, training, and medications is needed

*(University of Hawai'i Guam Conference Report).*

The findings from this report are similar to an assessment made by the Asian Pacific Islander American Health Forum. In a proposal submitted to HRSA on June 1, 2001, APIAHF proposes a project that provides a unique regional approach that can more effectively and efficiently address the lack of HIV care services in the jurisdictions. This project will build the HIV care service delivery capacity of the region, through overall regional activities coordination, regional capacity-building assistance, as well as one-on-one capacity building with each of the jurisdictions. The projects will 1) increase coordination and collaboration between the jurisdictions; 2) develop and support HIV training and technical assistance in the region; and 3) work with each jurisdiction to develop capacity for baseline standard of HIV care services.

Objectives include yearly training to increase capacity to serve HIV clients, standardized policies and procedures for the region to ensure client confidentiality and rights, enhancement of each jurisdictions' internal infrastructure to provide services, and the development of a shared medical records system between the jurisdictions. PIJAAG also suggests developing a tracking mechanism. This tracking mechanism should take into account the complexity of intra-jurisdiction coordination while protecting client confidentiality. Increased communication between the regions also would also help provide peer-to-peer support to both service providers and also potentially for clients. This regional model is an opportunity for the jurisdictions to develop not only their own infrastructure, but the region's as well.

### **2) FEDERAL, STATE, AND PRIVATE FUNDING FOR HIV PREVENTION AND CARE SERVICES**

Each Pacific Island jurisdiction also receives CDC funds for HIV prevention activities and community planning. Five of the six jurisdictions also receive Division of Adolescent School Health (DASH) funds. DASH funds the Youth Risk Behavior Survey that measures priority health-risk behaviors among youth, including HIV/STDs.

All jurisdictions will be receiving Title II funds this year, five for the first time, for the baseline amount (\$50,000) for HIV care services. Additionally, Guam receives some ADAP funds. These

Title II funds will help build some capacity in each jurisdiction, but will not address the regional approach needed to work effectively in the Pacific. Each jurisdiction will continue to develop its HIV care services through their newly awarded Title II funds. However, these jurisdictions are newly funded and will need on-going assistance to ensure each jurisdiction is able to provide a continuum of HIV care services appropriate to their area. At their base funding of \$50,000 per year, this is not enough to support a continuum of HIV care services. Sharing resources in the region to create a regional model will be critical in ensuring not only a continuum of HIV services, but also that all PLWHAs will have access to HIV primary care services, early intervention, and case management in the region.

Furthermore, Coral Life Foundation in Hagatna, Guam, the only HIV CBO in the region, also receives funding through the Guam Department of Public Health, CDC, and private foundations like the Gill Foundation and Mac Cosmetics.

## BACKGROUND ON THE PACIFIC ISLAND JURISDICTIONS

### GENERAL

The Pacific Island Jurisdictions are comprised of three U.S. territories and three U.S. freely associated states. U.S. territories include American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI) and Guam. U.S. freely associated states include the Federated States of Micronesia (FSM), the Republic of the Marshall Islands (RMI), and the Republic of Palau.

Contemporary histories of the Pacific Island jurisdictions are complex, with legacies of colonization by Spain, Germany, Japan, as well as the U.S. The current U.S. involvement in the region is equally complicated; issues of self determination, land rights, federal dependency, U.S. military presence, nuclear weapons testing and related illnesses, immigration policies, and labor conditions continue to dominate this relationship.

### THE PACIFIC ISLAND JURISDICTION REGION

- ξ All are predominately rural island communities, primarily organized by villages. Each jurisdiction has urban centers, though, which draw people in search of jobs and education.
- ξ The jurisdictions all have majority Pacific Islander and Asian populations.
- ξ The jurisdictions are very small. The largest, FSM, at 270 square miles (not all of which is inhabitable) is smaller than the state of Rhode Island. However, it occupies more than one million square miles of the Pacific Ocean and ranges 1,700 miles from East (Kosrae) to West (Yap) (*Office of the Insular Affairs State of the Islands Report 1999*).
- ξ While English is the language most commonly used in government business, English is not the language most commonly spoken at home in any of the jurisdictions (*OIA Report 1999*).
- ξ Each island has very distinct populations, geographies, cultures, languages, and economies. For example, Guam has one of the largest populations (154,623) on a single island, with \$19,000 per capita annual income; the Republic of Marshall Islands has a small population (68,126) spread out on 31 atolls, with \$1,670 per capita annual income (*Central Intelligence Agency World Factbook 2000*).
- ξ The availability of civic amenities such as power, sewage control, paved roads, water and food. Natural disasters (typhoons, cyclones, earthquakes, and tsunami) have continued to devastate the region and directly affect the region's access to reliable basic necessities.
- ξ Time zones and datelines vary greatly in the jurisdictions. For example, 4:00pm on Wednesday in San Francisco (7:00pm in Atlanta, GA; 1:00pm in Hawai'i), is 12:00pm on Wednesday in American Samoa, 9:00am on Thursday in Commonwealth of the Northern Mariana Islands, 9:00am on Thursday in Chuuk, Federated States of Micronesia, 10:00am on Thursday in Pohnpei, Federated States of Micronesia, 9:00am on Thursday in Guam,

11:00am on Thursday in the Republic of the Marshall Islands, and 8:00am on Thursday in Palau.

- ξ Average travel time to San Francisco, the closest U.S. continental city, from the Pacific Islands jurisdictions can take on average 20 hours. There are no direct flights. Monopolies in telecommunications and air travel have further isolated these island nations.
- ξ All jurisdictions have young populations. In comparison to the 1995 median age of 33.6 years in the U.S., the jurisdictions ranged from 28.1 years in Palau to 16.2 year in RMI (*OIA Report 1999*).
- ξ Each jurisdiction has a vibrant tourist economy. In 1996, Guam had 1,362,000 tourists visit; CNMI had 736,000; and Palau had 70,000.
- ξ Migration between islands is common, for historical, cultural, and economic reasons. The Compact of Free Association Act of 1988, which establishes the relationship between the U.S. and FSM and RMI, authorized immigration of FSM and RMI citizens into the U.S., its territories, and possessions. This has had significant impact on migration in the region. For example, preliminary results of Guam's 1997 census show that Guam's resident population from these nations has increase by about 4,568 persons since implementation of the Compact (*OIA Report 1999*). In addition, many Pacific Islanders travel to and from the continental U.S. and Hawai'i.
- ξ The jurisdictions have an influx of Asian foreign workers, coming primarily from China, Korea, Philippines, and Thailand. For example, the 1999 population of CNMI (79,000) has increased about 82% since 1980; most of this increase attributed for by non-resident workers and their families (*OIA Factsheet 2000*).
- ξ Economies of the Pacific Island jurisdictions range from subsistence economies to money economies.
- ξ There are few non-governmental agencies (in all areas of health and social services, including HIV/AIDS) in the Pacific jurisdictions. All the jurisdictions rely on the strengths of their health departments, hospitals, and Ministries of Health for the majority of their health care and social service needs.
- ξ Five of the six jurisdictions are receiving Title II funding for the first time this year.



Insert map of the Pacific region



**AMERICAN SAMOA**

**GEOGRAPHIC AREA:** Consists of 7 islands with a total land area of 76 square miles dispersed over 150 miles. It is the only jurisdiction in the Polynesia region of the Pacific Ocean (*Land area is slightly larger than Washington, D.C.*).

**PEOPLE:** American Samoans, together with Native Hawaiians, Maoris, Tongans and Tahitians are Polynesians.

**CULTURE:** *Fa'a*, meaning the Samoan way of life, has kept Samoans conscious of their ethnic traditions and flexible to withstand changes brought by foreign trade, military forces and missionaries. Samoan life revolves around the *aiga*, the extended family.

**LANGUAGES:** Official languages are Samoan and English.

**POPULATION:** American Samoa has a population 65,446 with 95% of the total population living in the urban center on the island of Tutuila.

**ETHNIC DISTRIBUTION:** Samoan (89%), Tongan (4%), Fijian, Tahitian and other (7%)

**LIFE EXPECTANCY:** 72 years

Insert map

**GOVERNMENT/ POLITICAL STATUS:** U.S. Territory. American Samoa is an unincorporated and unorganized territory and is administered by the U.S. Department of the Interior. It was relinquished through to the U.S. through deeds of cession in 1900. It is unincorporated because not all provisions of the U.S. Constitution apply to the territory. It is unorganized because U.S. Congress has not provided an organic act, which would provide for the organization of the government and its relationship to the federal government.

**ECONOMY:** Compromising 93% of the nation's economy, American Samoa's economy is heavily dependent on Federal expenditures and 2 tuna canneries. The remaining 7% stems from tourism, garment manufacturing and small businesses. Combined, the American Samoa government and canneries account for 61.5% of the employment in 1994.

**GDP:** \$150 million (1995 est.)

**GDP – PER CAPITA INCOME:** \$3,039 (1995 est.)

**UNEMPLOYMENT RATE:** 12% (1991)

**HEALTH ACCESS:** American Samoa has only 1 hospital. Basic preventative health services are delivered through 5 village dispensaries. All HIV and general health services are delivered through the Department of Health and the LBJ Tropical Medical Hospital. Medicare/Medicaid program does provide payment of medical services.

## **COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS**

**GEOGRAPHIC AREA:** Consists of 14 islands with a total land area of 176.5 square miles. The main islands are Saipan, Rota and Tinian. It is located in the Micronesia region of the Pacific Ocean (*Land area is 2.5 times the size of Washington D.C.*)

**CULTURE:** Chamorros share a common history and culture with the Chomorros of Guam. Also Carolinians share common histories with the people of the Republic of Palau and FSM.

**LANGUAGES:** Official languages are Chamorro, Carolinian and English. 86% of the population speaks a language other than English at home.

**POPULATION:** CNMI's population in 1998 is estimated to be about 79,429.

**LIFE EXPECTANCY:** 68 years

**MEDIAN AGE:** 17.2 years

**ETHNIC DISTRIBUTION:** Chamorros (31%), Carolinas (7%), other Micronesians (7%), Filipinos (33%) Japanese, Chinese, Koreans and other Asians (19%), Other (3%).

Insert map

**POLITICAL STATUS/ GOVERNMENT:** U.S. Territory. CNMI is a self-governing Commonwealth of the United States. The people of CNMI voted to join the U.S. in a 1975 act of self-determination and were granted U.S. citizenship in 1986.

**ECONOMY:** CNMI experienced dramatic economic growth over the past decade due to tourism, construction and the garment manufacturing industry.

**GDP:** \$524 million (1996 est.)

**GDP – PER CAPITA INCOME:** \$9,300 (1996 est.)

**UNEMPLOYMENT RATE:** 14%

**INDUSTRIES:** Tourism, construction, garment manufacturing and handicrafts

In CNMI, garment manufacturing thrives on a special exemption that allows CNMI garment factories to export into the United States without quotas or paying a customs duty. In recent years total garment shipments from CNMI to the United States has been steady increasing by more than 40% a year. Temporary workers comprise 69% of the total CNMI workforce in 1996.

Tourism has been increasing at an average of 30% per year.

**HEALTH ACCESS:** CNMI's Department of Public Health is the sole provider of comprehensive health services, with the Commonwealth Health center. CNMI has 2 sub-hospitals in Rota and Tinian.

Medicare/Medicaid program does provide payment of medical services.

**FEDERATED STATES OF MICRONESIA**

**GEOGRAPHIC AREA:** Consists of 607 small atolls and islands scattered over a million square miles, but constitutes only 271 square miles of land area. The distance from Kosrae State in the East and Yap state in the west is over 1,700 miles and covers 2 time zones. The country is divided into four island states: Yap, Chuuk, Kosrae and Pohnpei. It is located in the Micronesia region of the Pacific Ocean (*Land area is 4 times the size of Washington D.C.*).

**CULTURE:** The cultures of the FSM are tremendously diverse. Nine separate language with different dialects are spoken throughout the islands.

**LANGUAGES:** Trukese, Pohnpeian, Yapese, Kosraean and English are the official languages.

**POPULATION:** Federated States of Micronesia has a population of 127,616 (2000 est.).

(Chuuk; 50,000, Pohnpei; 35,000, Yap; 12,000, and Kosrae; 7,500).

**ETHNIC DISTRIBUTION:** Most of the population is Micronesian. Polynesia, other Pacific Islanders and Asian make up a small percentage.

**LIFE EXPECTANCY:** 68.3 years

Insert map

**POLITICAL STATUS/ GOVERNMENT:** FSM is a sovereign, self-governing state in free association with the U.S. The governments of FSM and U.S. signed the final version of the Compacts of Free Association in 1982. Under the Compacts, the status of free association recognized that FSM is a sovereign state with the capacity to conduct foreign affairs consistent with the terms of the Compacts.

**ECONOMY:** Economic activity consists primarily of subsistence farming and fishing. FSM is slowly moving into a monetary economy as the urban centers continue to grow. FSM possesses no significant exploitable natural resources but the ocean, in which FSM claims a large exclusive economic zone that straddles the world's richest tuna fishing grounds.

**GDP:** \$240 million (1997 est.)

**GDP – PER CAPITA INCOME:** \$2,000 (1997 est.)

**UNEMPLOYMENT RATE:** 27%

**INDUSTRIES:** Fishing, fish processing, tourism, construction, handicrafts

**HEALTH ACCESS:** FSM has 4 hospitals and 82 dispensaries as well as to provide dental services and medical supplies. Each of the 4 states maintains its own health and social service system with overall coordination, guidance and technical assistance by the national office in Pohnpei. Medicare/Medicaid program does not provide payment of medical services.

**GUAM**

**GEOGRAPHIC AREA:** Consists of a single island of 212 square miles. It is located in the Micronesia region of the Pacific Ocean (*Land area is 3 times the size of Washington D.C.*).

Insert map

**CULTURE:** Guam has evolved into a multi-ethnic society. Guam has no single ethnic group constituting more than 50% of the population although Chamorros make up the largest ethnic group.

**LANGUAGES:** Chamorro and English are the official language. Other Micronesian languages, Filipino and Japanese are also spoken.

**POPULATION:** The population is estimated to be 154,623 (2000 est.). The expanding 2 urban commercial centers are surrounded by suburban sprawl, undeveloped land and small 'family' ranches.

The U.S. Census Bureau definitions for rural and urban communities are not appropriate for Guam. Using this definition Guam's capital city of Agana would be considered to be a rural community, while Inarjan, an important agricultural area, would be considered to be urban.

**ETHNIC DISTRIBUTION:** Chamorro (47%), Filipino (25%), White (10%), Chinese, Japanese, Korean and other (18%)

**LIFE EXPECTANCY:** 77.78 years

**POLITICAL STATUS/ GOVERNMENT:** U.S. Territory. Guam is an unincorporated, organized territory of the United States. Guam was annexed, along with Puerto Rico and Hawai'i, after the Spanish-American War in 1898. The people of Guam were made U.S. citizens in 1950.

**ECONOMY:** Guam's economy is based on 2 main sources of revenue – tourism and U.S. military expenditures. Since the 1960s, Guam has been transitioning from the military into a tourism and market base.

**GDP:** \$3 billion (1996 est.)

**GDP – PER CAPITA INCOME:** \$19,000 (1996 est.)

**UNEMPLOYMENT RATE:** 2%

**HEALTH ACCESS:** HIV/AIDS Services in Guam are mainly delivered through the Department of Health along with the Southern Region Health Center, Northern Region Health Center and Coral Life Foundation, the region's only community based AIDS organization. There are also general health services through HMOs and private physicians.

Guam is currently the only jurisdiction in the region to offer ADAP to PLWAs, as well as Orasure testing.

Medicare/Medicaid program does provide payment of medical services.



**REPUBLIC OF THE MARSHALL ISLANDS**

**GEOGRAPHIC AREA:** Republic of the Marshall Islands consists of 5 islands and 29 atolls with a total land area of 181.3 square miles that spans a geographic region of 750,000 square miles. RMI is divided into 2 parallel channels: Ratak (Sunrise) Chain and Ralik (Sunset) Chain. It is located in the Micronesia region of the Pacific Ocean.

In the Ralik Chain, Ebeye Island, part of the Kwajalein Atoll is the main area of U.S. military test bombing and activities (*Land area is slightly larger than Washington D.C.*).

**PEOPLE/CULTURE:** Marshallese culture revolves around a complex clan system. Traditionally, the sea was a major source of food and a thoroughfare among atolls.

**LANGUAGES:** Marshallese (2 dialects) and English. Marshallese is a dialect of the Malayo-Polynesian family.

**POPULATION:** RMI has a population of 68,126 (2000 est.) with the majority of people concentrated in the 2 urban centers of Majuro and Ebeye.

**ETHNIC DISTRIBUTION:** Marshallese (96.9%), Other Pacific Islanders, Asians and Whites (3.1%)

**LIFE EXPECTANCY:** 65.5 years

**MEDIAN AGE:** 16.2 years

**POLITICAL STATUS/ GOVERNMENT:** RMI is a sovereign, self-governing state in free association with the U.S.. RMI and U.S. signed a final version of the Compacts of Free Association in 1983.

An obligation under the Compacts is the leasing of the islands in the Kwajalein Atoll to the U.S. for its military operations. These effects from the military operation, especially the test bombings, has had a significant impact on RMI's health, especially among cancer rates.

**ECONOMY:** RMI is a mixture of subsistence and monetized economy. Major restraint facing RMI's economic growth and development are the remoteness from major centers of trade, a small natural resource base and a population dispersed among numerous islands and atolls.

**GDP:** \$105 million (1998 est.)

**GDP – PER CAPITA INCOME:** \$1,670 (1998 est.)

**UNEMPLOYMENT RATE:** 16%

**HEALTH ACCESS:** RMI has 2 hospitals in Majuro and Ebeye, and 60 health centers in the outer atolls. The Department of Health administers and delivers most of the health services. Medicare/Medicaid program does not provide payment of medical services.


Insert map



**REPUBLIC OF PALAU**

**GEOGRAPHIC AREA:** Republic of Palau is made up of 200 islands stretching into an archipelago over 300 miles long. Palau's total land area is 196.10 square miles. The largest island, Baeldaob, accounts for 151 square miles. It is located in the Micronesia region of the Pacific Ocean (*Land area slightly more than 2.5 times the size of Washington D.C.*)

Insert map



**CULTURE:** Palauans are Micronesian with Malayan and Melanesian heritage.

**LANGUAGES:** Palauan, Sonsorolese, Tobi, Anguar and English are the official languages.

**POPULATION:** 19,129 (2000 est.), concentrated in Koror, the capital.

**GROWTH RATE:** 1.75% (2000 est.). Palau's population is growing rapidly as a result of foreign immigration. The demand for foreign labor, especially from Asia, will increase substantially in 2000-2005 period due to the projected demands of the construction industry and tourism industry.

**ETHNIC DISTRIBUTION:** Palauans make up the majority with a rising Asian immigrant population

**LIFE EXPECTANCY:** 68.47 years

**MEDIAN AGE:** 28.1 years

**POLITICAL STATUS/ GOVERNMENT:** Palau is a sovereign, self-governing state in free association with the U.S.. Palau and U.S. signed a final version of the Compacts of Free Association in 1994.

**ECONOMY:** One of the cornerstone's of Palau's economy is tourism. Since 1997, visitor arrivals have grown steadily (28% increase), with Asia being the main source. Tourism and the accompanying hotel and apartment construction industry are expected to lead Palau's economic growth over the next decade. Palau continues to rely on subsistence agriculture and fishing.

**GDP:** \$160 million (1997 est.)

**GDP – PER CAPITA INCOME:** \$8,800 (1997 est.)

**UNEMPLOYMENT RATE:** 7%

**HEALTH ACCESS:** Palau has 2 private medical clinics and 1 public hospital. HIV/AIDS Services are primarily delivered through the Ministry of Health. The U.S. Medicare/Medicaid program does not provide payment of medical services.





# Notes

Handwriting practice lines on a lined paper. The page features horizontal red lines for writing. There are three binder holes visible on the right side of the page.

August 6, 2002

Dr. Deborah Parham, Ph.D., M.S.P.H., R.N.,  
Associate Administrator  
Health Resources and Services Administration  
HIV/AIDS Bureau  
5600 Fishers Lane  
Parklawn Building, Room 7-00  
Rockville, MD 20857

Dear Dr. Parham,

I am writing as the spokesperson of the Pacific Island Jurisdictions AIDS Action Group (PIJAAG) to request a meeting with you at the Ryan White CARE Act Grantees' Conference to be held in Washington DC August 20-23, 2002. We would like to have a dialogue with you about the opportunities and challenges for improved HIV/AIDS care services in the Pacific Island jurisdictions and possible strategies to address these issues.

Those of us delivering HIV/AIDS prevention and care services in our respective jurisdictions have become painfully aware that the prevalence of HIV/AIDS is much greater than originally believed. Currently, the region is working with the CDC to strengthen its testing, surveillance, and reporting capacity to accurately document the growing number of HIV/AIDS cases in the region. While the absolute numbers appear small, the impact is great relative to the size of our populations and the existing infrastructure for care services. Twenty years into this epidemic even the most basic treatment facilities are not available in our island communities. PIJAAG already has met with CDC leadership to begin addressing testing, surveillance and other unique needs of the Pacific. Our meeting with you and other HRSA representatives will help us develop the continuum of care in our islands for People Living With HIV/AIDS.

At the meeting, we hope to have PIJAAG members, representatives from each of the six Pacific Island jurisdictions as well as the Asian & Pacific Islander American Health Forum (APIAHF), a national health advocacy organization that has provided technical assistance to the jurisdictions for several years.

Please contact me by email at [vincecrisotomo@hotmail.com](mailto:vincecrisotomo@hotmail.com) to begin discussions on these recommendations and plan our meeting. For your convenience (as Guam and Washington have a 14 hour time difference), you may contact Prescott Chow to set up the meeting (415-954-9970). Prescott is the Program Manager for the HIV Capacity building Assistance Program at APIAHF, and he communicates regularly with PIJAAG.

Attached is background information on PIJAAG and the Pacific Island Jurisdictions, a set of recommendations and requests to improve HIV/AIDS services in the region, and an overview of the issues regarding HIV and AIDS in the Pacific.

Thank you for your attention. We look forward to meeting with you next month.

Sincerely,

Vincent Crisostomo  
Pacific Island Jurisdictions AIDS Action Group Spokesperson

cc: Ginny Bourassa, Deputy Branch Chief, Technical Assistance Branch, Division of Training and Technical Assistance (DTTA)



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## BACKGROUND: Pacific Island Jurisdictions AIDS Action Group (PIJAAG)

### WHO IS PIJAAG?

In February 2001, representatives from five of the six Pacific Island Jurisdictions (American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam and Republic of Palau) met for five days in Honolulu, Hawai'i to discuss the state of HIV prevention and care services in their respective jurisdictions. This group, which included AIDS directors, program staff, community stakeholders, as well as CDC funded capacity building assistance providers, discussed the shared experiences of the Pacific Island jurisdictions. From these discussions, the group began formulating a regional plan to address HIV/AIDS. The group met several times after that initial meeting, with the Republic of the Marshall Islands also joining the newly formed group. With all the six Pacific Island jurisdictions together, the Pacific Island Jurisdictions AIDS Action Group (PIJAAG) formed and created the following mission statement.

### PIJAAG MISSION STATEMENT

We are representatives of the United States-affiliated Pacific Island Jurisdictions standing united to speak in one voice around the shared issues of HIV/AIDS in our island communities.

- ξ We advocate for the provision of quality HIV prevention and care services in the region.
- ξ We advise national, international, and local policy entities on HIV/AIDS.
- ξ We strengthen and coordinate AIDS activities through the sharing of information and resources within the region.

PIJAAG strongly advocates for changes in the response to the AIDS epidemic in the Pacific region, both internally as a region and externally from federal agencies like the Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA). PIJAAG sees the need to develop a regional model of HIV prevention and services.

PIJAAG represents those infected, affected and those whose role it would be to deliver the HIV/AIDS services needed in our communities. PIJAAG feels strongly that twenty years into the epidemic with no relief in sight, several changes need to be made to respond to the AIDS epidemic in the Pacific region.

### PIJAAG MEMBERSHIP

- ⑨ Health Department / Ministry of Health representatives from
- ⑨ All six Pacific Island jurisdictions
- ⑨ CBO AIDS Service Organization representatives
- ⑨ Community Planning Group and Ryan White Planning Council members
- ⑨ Consumers (Persons infected/affected by HIV/AIDS, and their support networks)

### Other PIJAAG Supporters

- ⑨ Federal agencies representatives
- ⑨ Capacity building assistance providers

### PIJAAG Accomplishments and Activities

- ⑨ Meeting with CDC leadership (center, division, and branch heads) to discuss recommendations for improving HIV prevention efforts
- ⑨ Meeting with HRSA Region IX office to discuss Title II activities
- ⑨ Meeting with CDC Surveillance branch to discuss improving HIV surveillance efforts in the region
- ⑨ Submitted HRSA 2001 Title III Regional Capacity building Grant (approved but not funded)
- ⑨ Submitted CDC Conference Grant (approved but not funded)

### PIJAAG Successes

- ⑨ Supporting each jurisdiction to receive HRSA Title II Funds
- ⑨ Through advocacy, CDC has increased base awards to the region by \$600,000
- ⑨ Through advocacy, CDC is currently working with the jurisdictions to build regional HIV testing infrastructure
- ⑨ HRSA and CDC continue to work with PIJAAG to solve specimen transportation issues that have hampered HIV test confirmations
- ⑨ Peer-to-peer training and support through inter-jurisdiction activities
  - counseling testing training
  - HIV program infrastructure technical assistance
  - Regional case conferencing

## FOREWORD

The Pacific Island Jurisdictions are comprised of three U.S. territories and three U.S. freely associated states. U.S. territories include American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI) and Guam. U.S. freely associated states include the Federated States of Micronesia (FSM), the Republic of the Marshall Islands (RMI), and the Republic of Palau.

All the jurisdictions are predominately rural communities with a majority Pacific Islander and Asian populations. Availability of power, sewage control, paved roads, water, food and other basic infrastructure needs are continuing issues in many of the Pacific Island jurisdictions. All have young, sexually active populations, with high rates of STDs and teenage pregnancy. Each jurisdiction is dealing with an influx of tourists and foreign workers. Migration between islands is common. Many islanders travel to and from the continental U.S. Some of the jurisdictions are dealing with increased commercial sex work.

There is no comprehensive continuum of HIV care services within any of the jurisdictions. Furthermore, there is a lack of coordinated HIV care services between them. There are few non-governmental agencies (in all areas of health and social services, including HIV/AIDS) in the Pacific Island jurisdictions. All rely on the strengths of their health departments and Ministries of Health. Five of the six jurisdictions are receiving Title II base funding for the first time this year (FY2002).

### HIV SERVICES IN THE PACIFIC ISLAND JURISDICTIONS

Health care delivery in the region comes under the Department or Ministry of Health and is divided between the hospital services and the public health departments. HIV Services, including prevention and care, are provided mainly through the public health departments. While there are some private providers that see PLWHA in Guam and CNMI, most of the jurisdictions do not have this luxury. In all of the jurisdictions, the health departments play a key role in the provision of HIV services. However, in most jurisdictions, these programs have only a handful of staff, with HIV programs usually combined with STD programs.

The only AIDS service organization in the region, Coral Life Foundation, has two staff. Founded in 1993, Coral Life Foundation was the first non-governmental organization based in the Pacific Island region to receive federal funds for HIV prevention in 1999.

### BARRIERS THAT IMPACT ACCESS TO CARE

The main barriers for PLWHA in the Pacific Island Jurisdictions are the lack of a continuum of HIV care services in each jurisdiction and the lack of coordinated care services in the region. PLWHA may not be accessing services because, in most jurisdictions, there are no services to access.

### BARRIERS THAT IMPACT ACCESS TO CARE IN THE REGION

- ⑨ The lack of HIV care services in each jurisdiction.
- ⑨ The lack of coordinated HIV care services throughout the region has repeatedly been reported as a barrier to care with migration throughout the region. For example, PLWHA must have their HIV positive status confirmed through another HIV test before accessing services in another jurisdiction. This can be an extremely long process (*PIJAAG April 2001 meeting*).
- ⑨ The lack of case management services means PLWHA need to be able to self-advocate and maneuver through a health care system. As these systems are not HIV-specific care services presents other barriers.
- ⑨ Confidentiality issues and fear of being ostracized still are common concern of PLWHA in the region. Many seek services elsewhere, only seek services at end stages of the disease, or don't seek services at all.
- ⑨ Currently available continuum of HIV care services (Honolulu, Hawai'i) are inaccessible due to the distance and the cost.
- ⑨ Currently, no jurisdiction is providing outreach for HIV care services (presumably because the services are not available)
- ⑨ There still exists a denial in the jurisdictions that HIV/AIDS is in the community and a denial of the possibility that one is at risk (*PIJAAG February 2001 meeting*) People therefore do not access care services because they do not think it is possible for them to be HIV positive.



## RECOMMENDATIONS AND PROPOSED IMPLEMENTATION STEPS FOR IMPROVING HIV/AIDS SERVICES IN THE PACIFIC

The Health Resources and Services Administration has been active in supporting planning and coordination activities in the Pacific Island jurisdictions that would improve the access to and quality of health services in the region. HRSA commissioned the important Institute of Medicine (IOM) report, "Pacific Partnerships for Health: Charting a New Course," issued in 1998. That report provided a comprehensive overview of the health issues and health infrastructure needs of the Pacific region. In 1998, HRSA also convened the Pacific Basin Health Summit, to review the IOM report and to respond to some of its recommendations. In 1999, HRSA began its Pacific Basin Telehealth Initiative, utilizing telemedicine and distance education as a key strategy for improving primary care delivery, enhancing prevention activities and supporting the training of health personnel in the Pacific region. PIJAAG's proposed recommendations are consistent with and will continue to build upon these prior activities undertaken by HRSA.

*PIJAAG proposes the following recommendations to HRSA to create a continuum of care and treatment for People Living With HIV/AIDS in the Pacific region. This continuum needs to be developed in partnership with the Pacific Island jurisdictions, incorporating the unique geographic, cultural, political, and economic issues of the region. Detailed analyses of each recommendation are on the following pages.*

### INDIVIDUAL JURISDICTION INFRASTRUCTURE DEVELOPMENT (INTRA-JURISDICTIONAL DEVELOPMENT)

**RECOMMENDATION 1: HRSA should assure that at least one HIV/AIDS care service site per Pacific Island Jurisdiction be established to provide comprehensive HIV/AIDS care services for People Living With HIV/AIDS, including access to treatment and support services.**

#### **RATIONALE:**

Currently, there is no comprehensive continuum of HIV/AIDS services available within any of the six Pacific Island Jurisdictions. For example, Guam, the only jurisdiction in the region funded through HRSA Title II for over two years, still does not have the capacity to provide case management to its People Living With HIV/AIDS constituency. The other jurisdictions, having received Title II base funding for the first time in 2001, have only just begun to address HIV/AIDS care issues. Additionally, the unique conditions of each jurisdiction have added to the unequal range of available HIV/AIDS services.

The region needs HRSA's assistance to build the HIV/AIDS care capacity for each of the jurisdictions, while still acknowledging the different needs of each jurisdiction. The infrastructure needs, for example, of Guam's HIV/AIDS care program are very different from the infrastructure needs in Federated States of Micronesia, where the availability of basic HIV/AIDS primary care is still a challenge. With a tailored system, developing programs could begin to address gaps in services while other jurisdictions with more established infrastructure and program capacity could further enhance their care programs. Using this approach to develop at least one site per jurisdiction

will provide local communities access to comprehensive HIV care and treatment as the needs and capacities increase over time.

In addition to one HIV/AIDS care service site, the Federated States of Micronesia needs one site *per state* due to huge geographic distances between each of its four island states. The Federated States of Micronesia's national borders stretch over a million miles across the Pacific Ocean. Compounding this expanse, some states do not have direct flight access to the capital state of Pohnpei. For example, the residents of the state of Yap need to fly through Guam to get to Pohnpei; some of the outer island residents in the state of Chuuk need to take a 24-hour journey by boat to reach the capital.

HRSA needs to consider the geographic, economic, political, and cultural uniqueness in providing HIV/AIDS care within each jurisdiction. For instance, American Samoa is closer geographically and culturally/ethnically to Hawai'i (both are Polynesian); the other jurisdictions are located in a different time zone (one day ahead) and are culturally/ethnically Micronesian. In addition, the cost of doing business, the health system, and infrastructure for HIV/AIDS care can vary from jurisdiction to jurisdiction. These jurisdiction-specific factors should be addressed in any strategy for the region.

#### **PROPOSED IMPLEMENTATION STEPS:**

1. Any strategy for the Pacific Island Jurisdictions should recognize the geographic and cultural uniqueness of the area, especially American Samoa and the Federated States of Micronesia and develop a comprehensive continuum of HIV/AIDS care site per jurisdiction plus one per state in Federated States of Micronesia.
2. HRSA should work with each jurisdiction to develop the capacity for baseline standard of HIV/AIDS care services, with a tailored approach that supports infrastructure building and addresses the unique needs of all jurisdictions.
3. HRSA should work with the jurisdictions to develop levels of funding that reflect the cost of doing business in the Pacific region.

#### **REGIONAL APPROACH (INTER-JURISDICTIONAL COORDINATION)**

**RECOMMENDATION 2: HRSA should develop a regional strategy for the Pacific Island Jurisdictions to support on-going regional HIV/AIDS planning, coordination and capacity building.**

#### **RATIONALE:**

The Pacific Island jurisdictions, with six jurisdictions spread over an area spanning as wide as the continental U.S., nevertheless has populations and histories tied closely together. Migration between the island nations is common, due to cultural, economic, and political interdependencies. The current and historic ties between the jurisdictions suggest that in addition to an individual jurisdiction approach, a regional HIV/AIDS strategy needs to be developed.

HRSA is already using regional approaches in two areas: HRSA's Border Health Program for the U.S. Mexico border region and the U.S.-Caribbean Collaboration (part of HRSA's Global AIDS Initiative) for the Caribbean region. Both of these programs recognize not only the rapid spread of



HIV/AIDS, but also the unique regional public health context in which HIV/AIDS exists in these areas.

Currently, there is a lack of coordinated HIV/AIDS services between the jurisdictions in the region. PIJAAG has already engaged a regional approach to support HIV/AIDS planning, coordination and capacity building. HRSA's support in augmenting this coordination will support HIV/AIDS services through the following:

1) Reduce Geographic Isolation

The Pacific Island Jurisdictions are geographically very far from the continental U.S., Alaska, and Hawai'i. These Island nations face similar barriers in health care delivery. For example, while medications are available primarily in Guam and CNMI, the ADAP formulas do not account for the higher poverty rates within this region, and the increase cost of drugs and delivery, both of which increase the likelihood of ADAP need by people living with HIV/AIDS in the region.

Adding to the burden of disease, severe shortages of health professionals in most of the region, as demonstrated by high HPSA scores, limit access of People Living With HIV/AIDS to providers with competency in treating AIDS (*AETC Training Summary 2000*). The regional approach will also support peer-to-peer training and mentorship to support improved care in the region, which will successfully reduce the burden of HIV in these island communities.

2) Address Migration Impact

Migration between the different Pacific Island jurisdictions is common for economic, cultural, and familial reasons, as well as migration between the islands, Hawai'i, and the continental U.S.. A regional strategy could address the impact of migration on HIV/AIDS service provision in each jurisdiction and the region.

3) Honor Pacific Island Jurisdiction Realities and Strategies

The Pacific Island jurisdictions face numerous geographic, cultural, political, and economic obstacles, distinct from the continental U.S., which contribute to the challenges in implementing comprehensive services for People Living With HIV/AIDS. For example, traditional ideas of "continuity of services" suggest that physical location of services be in close proximity of each other, to allow for easy client access. However, assurance of confidentiality in the islands, where "everyone knows everyone" presents additional challenges in these small communities. Providers acknowledge that Pacific Islanders may be testing off-island because of the lack of confidentiality available for HIV testing. One answer may be to locate HIV/AIDS services remote from other services to address confidentiality issues. However, this would contradict the traditional concept of "continuity of services".

*In most jurisdictions, despite some efforts to the contrary, there is little protection of patient's confidentiality and everyone knows who is being treated for any disease - including HIV...*

- PAETC Report 2000

This need for regional coordination has been also been assessed by the jurisdictions themselves. For example, in a January 2001 HIV/AIDS conference for physicians, nurses, and other health care

professionals in the Pacific Island region, the participants identified five areas of need for the management of HIV in the jurisdictions (*University of Hawai'i Guam Conference Report*).

- 1) Communication among the jurisdictions needs to be improved, including the sharing of information about migrating PLWHA throughout the region. Communication between the regions also would help peer-to-peer support.
- 2) Communication and support within each jurisdiction is needed to coordinate HIV care services.
- 3) The jurisdiction needs to have access to information from outside the region.
- 4) Training for health care providers and the community-at-large on the continuum of HIV related issues and community mobilization strategies are needed.
- 5) Funding for programs, training, and medications is needed.

**PROPOSED IMPLEMENTATION STEPS:**

1. A regional strategy, similar to HRSA's Caribbean Initiative and HRSA's Border Health Program, should be developed to focus on issues unique to the Pacific Island Jurisdictions. This strategy could include regional collaboration and coordination activities supported through region-specific allocated funds.

**COORDINATED APPROACH FOR HIV/AIDS CAPACITY BUILDING AND PLANNING**

**RECOMMENDATION 3: HRSA should enhance HIV/AIDS capacity building and planning efforts in each Pacific Island Jurisdictions and the Pacific region as a whole.**

**RATIONALE:**

*Capacity building and funding of Asian American and Pacific Islander communities that serve smaller, more geographically isolated or emerging populations are needed. Government funders have little knowledge of these communities and the emerging organizations in those communities have little knowledge of the funding opportunities available.*

*- Interim report of the President's Advisory Commission on Asian Americans and Pacific Islanders, A People Looking Forward: Action for Access and Partnerships in the 21st Century*

On-going, sustained HIV/AIDS capacity building assistance needs to be provided in the Pacific to ensure the development of continuum of care for each jurisdiction and the region overall. These trainings that are offered by capacity building assistance or technical assistance providers should meet the needs of the Pacific Island jurisdictions. However, geographic isolation of the region, travel expense and difficulties, differing time zones, as well as some providers' general lack of knowledge about the Pacific, continues to make technical assistance provision in the region difficult. The region has also experienced patronizing attitudes from some providers, with assistance provided based on assumed needs, not ones expressed by the jurisdictions. The jurisdictions need sustained, on-going culturally appropriate capacity building assistance; the Pacific Island jurisdictions must be involved in determining their capacity building assistance needs as well as the selection of the most appropriate capacity building assistance providers to deliver the services.

Some successful relationships have formed between the jurisdictions, PIJAAG, and capacity building assistance providers. HIV capacity building assistance providers APIAHF, Asian & Pacific Islander Wellness Center, the Association of Asian Pacific Community Health Organizations, and

the Pacific AIDS Education Training Center have long histories with the region. APIAHF and Asian & Pacific Islander Wellness Center are primarily funded to provide assistance in HIV prevention, but have also been working with the jurisdictions on comprehensive continuum of services, including HIV/AIDS care activities. As HIV/AIDS unfolds in the region, the need for capacity building assistance is becoming more urgent.

However, funds to support on-going assistance have not been adequate, given the huge travel costs between the region and these continental U.S.-based capacity building assistance providers. These relationships need to be supported through adequate resource allocated specifically to capacity building assistance provision in the Pacific.

Last year, APIAHF and PIJAAG submitted a HRSA Title II Capacity building grant proposal to address regional as well as individual jurisdiction capacity building needs. While approved, this proposal was not funded. We continue to seek funds to support these activities.

PIJAAG, APIAHF, Asian & Pacific Islander Wellness Center, CDC, and each of the Health Department/Ministries of Health are supporting a regional HIV skills-building conference and training in Palau in February 2003, currently focusing on HIV prevention training and technical assistance. With HRSA's participation and support, this regional conference provides a timely opportunity to also enhance HIV/AIDS care services, training and planning for the region.

Additionally, new models need to be explored that can site a capacity building assistance provider in the region. Currently, none in the region exist. Capacity building assistance needs to be easily accessible and preferably provided on-site. This ultimately means capacity building assistance providers need to be located and sustained in the region itself.

HRSA's on-going commitment for the capacity building assistance needs of the region is critical to the development of HIV continuum of care for People Living With HIV/AIDS in the Pacific. Sustained capacity building assistance, through providers that have a strong history with the region, needs to be funded.

**PROPOSED IMPLEMENTATION STEPS:**

1. HRSA should involve the Pacific Island Jurisdictions in the selection of capacity building assistance providers for the Pacific region.
2. HRSA should support on-going regional capacity building assistance and training through providers such as APIAHF, Asian & Pacific Islander Wellness Center, and the AIDS Education Training Centers.
3. HRSA should support a Pacific regional model of HIV Capacity building, similar to its Title III Capacity building program.
4. HRSA should support at least one HIV Capacity building project for each Pacific Island jurisdiction.
5. HRSA should support the upcoming Pacific regional HIV skills-building training in Palau, February 2003.



## COORDINATED SUPPORT AND MANAGEMENT BY HRSA AND OTHER FEDERAL AGENCIES

**RECOMMENDATION 4: HRSA should enhance coordination between federal agencies and programs in the Pacific region.**

### **RATIONALE:**

The Pacific Island jurisdictions have integrated HIV/AIDS prevention and care programs that are often managed by the same person. HRSA is currently coordinating communication between HRSA-HAB and other HRSA programs in the Pacific through HRSA's Region IX office. We thank HRSA for these efforts. In addition, however, we would like HRSA's on-going involvement in inter-agency coordination. Communication between HRSA and CDC is crucial for ensuring that the Pacific Island jurisdictions are supported to develop and provide a continuum of care for their constituents. For example, the Pacific Island jurisdictions are facing many barriers in surveillance collection and reporting (i.e. transportation barriers that lead to inability to confirm HIV tests, need for updated surveillance software, lack of funding for surveillance activities). PIJAAG is working with CDC and HRSA to resolve some of the barriers but this takes time. Because so much of HRSA's funding decisions are based on surveillance data, it is crucial that HRSA continues its involvement in inter-agency efforts to support the jurisdictions' surveillance capacity building.

### **PROPOSED IMPLEMENTATION STEPS:**

1. HRSA should continue coordination with CDC along with each Pacific Island jurisdiction to build surveillance infrastructure in the region.
2. HRSA should coordinate efforts with other agencies in the Department of Health and Human Services (HHS). In addition, HRSA should convene at least one annual face-to-face meeting that is attended by representative from the Pacific Island jurisdictions, HRSA program and other HHS programs, such as the CDC, that serve the Pacific.
3. HRSA should advocate for and participate in the creation of an inter-HHS-agency group for Pacific Island affairs. This would be useful for coordination and maximizing our efforts and limited resources. One or two people in each jurisdiction are often coordinating several HRSA programs as well as other HHS agencies (CDC, SAMHSA). The Department of Interior has set this example by convening the Inter-Agency group on Insular Affairs (IGIA).

## OVERVIEW OF HIV AND AIDS IN THE PACIFIC REGION

The Pacific Island jurisdictions face a multitude of care and treatment issues that emphasize the need for a comprehensive continuum of HIV/AIDS services in each jurisdiction and coordinated HIV/AIDS care and treatment services in the region. The following overview outlines the critical issues currently facing the Pacific Island jurisdictions.

### I. HIV/AIDS SURVEILLANCE

#### A. REPORTING

There are severe discrepancies between the numbers of HIV/AIDS cases reported by the Pacific Island jurisdictions themselves versus the numbers reflected by the CDC HIV/AIDS surveillance reports. At an August 1999 Counseling Testing Referral Partner Notification training held specifically for the Pacific Island jurisdictions and at an April 2001 meeting between PIJAAG members and the CDC surveillance branch, CDC were informed that HIV cases reported from the jurisdictions and sent to Atlanta, had not reached the CDC Surveillance branch. CDC is currently investigating these discrepancies and is working with each jurisdiction on collection and reporting. In the meantime, the Jurisdictions have reported their updated cases in both their 2000 CDC applications for baseline funding as well as their 2001 HRSA Title II applications. These on-going issues regarding surveillance again highlight the need for prioritized attention from federal agencies. The following tables outline the number cases reported from the Pacific Island jurisdictions and the number of cases reported in CDC's HIV/AIDS surveillance report.

**TABLE I.**

CASES REPORTED (through 2002) (reported directly from the Pacific Island jurisdictions)

JURISDICTION	Cumulative HIV Cases*	Cumulative AIDS Cases**	Number of known deaths (since 1985)***
American Samoa	1	0	6
CNMI	23	2	6
FSM - Yap	3	Not known	1
FSM - Chuuk	20	Not known	9
FSM - Pohnpei	0	0	0
FSM - Kosrae	2	Not known	2
Guam	171	75	45
Marshall Islands	7	2	2
Palau	2	0	2

\* includes un-confirmed (Western blot) cases

\*\* includes cases diagnosed symptomatically

\*\*\* includes figures from Pacific AIDS Education Training Center survey of medical providers

**TABLE II.** CDC's HIV/AIDS surveillance report through June 2001 (Vol. 13, No. 1)

PERSONS LIVING WITH HIV/AIDS (up to June 2001)

Area of residence	Living with HIV	Living with AIDS	Cumulative Living with HIV/AIDS
Guam	50	29	79
Pacific Islands	-	2	2

**TABLE III.** CDC's HIV/AIDS surveillance report through June 2001 (Vol. 13, No. 1)

HIV/AIDS CASES (up to June 2001)

Area of residence	Cumulative HIV*	Cumulative AIDS
Guam	55	55
Pacific Islands	Not reported	4

\*from areas with confidential HIV infection reporting



In comparison with Table I., it is a clear that there is a large discrepancy with case reporting.

With increasing numbers of indigenous cases, there is an increasing need for disaggregated data for each jurisdiction instead of collapsing all data from five of the jurisdictions into "Pacific Islands".

## B. HIV CONFIRMATORY TESTING AND CD4 TESTING

All jurisdictions provide HIV testing by blood, Orasure and/or rapid testing. For all jurisdictions except for Guam, HIV tests must be sent off island to Guam, Hawai'i, continental United States or Australia. Long waits for test results may occur, sometimes up to 2 months as in a case with American Samoa. Currently confirmatory tests and CD4 tests cannot even be performed with three of the Pacific Island jurisdictions. FSM, Palau and RMI currently are having problems with the only air carrier for the region, Continental Micronesia, which refuses to transport "infectious agents", even if the specimens are properly packaged by trained lab technicians. The lack of transportation also prohibits CD4 testing needed for basic ongoing HIV/AIDS care and treatment, AIDS diagnosis, and reporting.

CDC is currently working with FSM to get their growing number of new cases confirmed in Atlanta and reported. PIJAAG members along with CDC and HRSA representatives are currently working with Continental Airlines and their pilots to resolve this ongoing issue.

## II. NUMBER OF PEOPLE LIVING WITH HIV/AIDS (PLWHA) IN NEED OF CARE

Because of frequent migration between jurisdictions, as well as the desire for people diagnosed off-island to return home in the late stages of the disease, oftentimes, the number of cases reported on each jurisdiction does not reflect the actual number of People Living With HIV/AIDS (PLWHA) in need of care. For many Pacific Islanders, cultural and linguistic as well as familial ties bring many PLWHAs home when they become sick and require care (*Pacific AIDS Education & Training Report 2000*). For example in 2000, American Samoa reported zero HIV/AIDS cases, but had six PLWHA, who were not tested on the island and came to American Samoa with end-stage AIDS, to provide care services (*PAETC report 2000*). In a training conducted by the Pacific AIDS Education Training Center (PAETC) in 2002, medical providers from each Pacific Island jurisdiction were surveyed on the actual number of PLWHA on each jurisdiction. that were accessing care and treatment services.

**TABLE IV.**

PEOPLE LIVING WITH HIV/AIDS (PAETC training in 2002)

JURISDICTION	PLWHA (as of 2002)
American Samoa	2
CNMI	6
FSM - Yap	1
FSM - Chuuk	13
FSM - Pohnpei	0
FSM - Kosrae	1
Guam	101
Marshall Islands	7
Palau	2
<b>TOTAL</b>	<b>133</b>

### III. CURRENT INFRASTRUCTURE FOR HIV/AIDS SERVICE DELIVERY

#### A. OVERALL HEALTH SERVICE DELIVERY

Health care delivery in the region comes under the Department or Ministry of Health and is divided between the hospital services and the public health departments. There are few non-governmental agencies (in all areas of health and social services, including HIV/AIDS). All the jurisdictions rely on the strengths of their health departments, hospitals, clinics and Ministries of Health for the majority of their health care and social service needs.

#### B. HIV/AIDS SERVICE DELIVERY INFRASTRUCTURE

HIV/AIDS Services, including prevention and care, are provided mainly through the public health departments. While there are some private providers that see PLWHA in Guam and CNMI, most of the jurisdictions do not have this luxury. In all of the jurisdictions, the health departments play a key role in the provision on HIV/AIDS services. However these programs have only a handful of staff who manage HIV prevention and care programs in addition to other health programs such as STDs, maternal & child health, tuberculosis and hepatitis B.

#### C. SERVICE RESOURCE INVENTORY

TABLE V.

JURISDICTION	Outreach	Pre-test Counseling	Testing	Post-test Counseling	Partner Notification	Individual Level Interventions	Group Level Interventions	Community Level Interventions	Media	Referrals	Primary Care	Outreach to PLWA	Early Intervention Services	Medication Availability	ADAP funding	Case Management	Access to Confirmatory/ CD4 Lab
CNMI	X	X	X	X	X	X	X	X	X			*4		X	X	*4	X
FSM-Pohnpei	X						X	X	X					X			
FSM-Chuuk	X		X		X	X	X	X	X					*3			
FSM-Yap	X						X	X	X					*3			
FSM-Kosrae	X													*3			
Guam	X	X	X	X	X	X	X	X	X	X	X	*4	*4	X	X	*4	X
Palau	X	X	X	X	X	X	X	X	X					*3			
RMI	X	X	X	X	X	X	X	X	X		*4			X	X		
American Samoa	X	X	X	X	X	X	X	X	X					*3			

Prevention -----! Care

X-Currently exists    \*1-Needle Sticks    \*2-No Curriculum    \*3- Not Routinely Available    \*4- Currently being planned/ implemented

Though an initial reading may indicate that a fair amount of HIV/AIDS services is currently being provided, further investigation is needed to understand the full scope of the situation in the region. The availability of service and level of program development vary from each jurisdiction since five out of the six are receiving Title II funds for the first time in 2001.

#### IV. CURRENT PLANNING AND CAPACITY BUILDING NEEDS

It is recognized that all jurisdiction's provide primary care to people in need of services, including PLWHA, through their public health care systems. These systems alone are not equipped with the complexity and specialization needed to adequately provide HIV/AIDS care to PLWHA. Only Guam currently has the capacity to provide some HIV/AIDS-specific primary care services. The need for capacity building assistance in the jurisdictions is real and apparent.

The Guam Conference Report from the University of Hawai'i on its recent HIV/AIDS conference (January 2001) for physicians, nurses, and other health care professionals in the Pacific Island region identified five areas of need for the management of HIV in the jurisdictions.

- 1) Communication between the jurisdictions needs to be improved, including the sharing of information about migrating PLWHA throughout the region.
- 2) Communication and support within each jurisdiction is needed to coordinate HIV care services.
- 3) The jurisdiction needs to have access to information from outside the region.
- 4) Training for health care providers and the community-at-large on the continuum of HIV related issues and community mobilization strategies are needed.
- 5) Funding for programs, training, and medications is needed.

*(University of Hawai'i Guam Conference Report).*

The findings from this report are similar to an assessment made by the Asian Pacific Islander American Health Forum, a national capacity building assistance provider. In an approved yet unfunded proposal submitted to HRSA for Title II funds on June 1, 2001, APIAHF and PIJAAG proposed a project that would provide a unique regional approach that can more effectively and efficiently address the lack of HIV/AIDS care services in the jurisdictions. This project would build the HIV/AIDS care service delivery capacity of the region, through overall regional activities coordination, regional capacity-building assistance, as well as one-on-one capacity building with each of the jurisdictions. The project would 1) increase coordination and collaboration between the jurisdictions; 2) develop and support HIV/AIDS training and technical assistance in the region; and 3) work with each jurisdiction to develop capacity for baseline standard of HIV/AIDS care services. Objectives included yearly training to increase capacity to serve HIV/AIDS clients, standardized policies and procedures for the region to ensure client confidentiality and rights, enhancement of each jurisdictions' internal infrastructure to provide services, and the development of a shared medical records system between the jurisdictions. PIJAAG also suggested developing a tracking mechanism. This tracking mechanism would take into account the complexity of intra-jurisdiction coordination while protecting client confidentiality. Increased communication between the regions also would help provide peer-to-peer support to both service providers and also potentially for clients. This regional model would be an opportunity for the jurisdictions to develop not only their own infrastructure, but the region's as well.

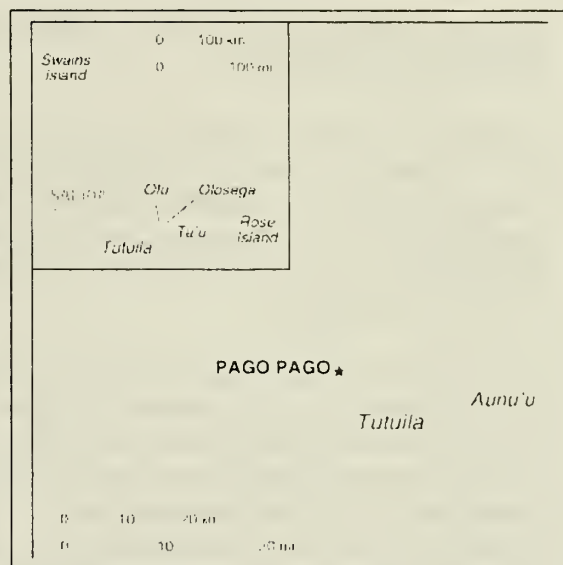


## AMERICAN SAMOA

**GEOGRAPHIC AREA:** Consists of 7 islands with a total land area of 76 square miles dispersed over 150 miles. It is the only jurisdiction in the Polynesia region of the Pacific Ocean (*Land area is slightly larger than Washington, D.C.*).

**PEOPLE:** American Samoans, together with Native Hawaiians, Maoris, Tongans and Tahitians are Polynesians.

**CULTURE:** *Fa'a*, meaning the Samoan way of life, has kept Samoans conscious of their ethnic traditions and flexible to withstand changes brought by foreign trade, military forces and missionaries. Samoan life revolves around the *aiga*, the extended family.



**LANGUAGES:** Official languages are Samoan and English.

**POPULATION:** American Samoa has a population 57,291 (2000 Census) with 95% of the total population living in the urban center on the island of Tutuila.

**ETHNIC DISTRIBUTION:** Samoan (88.2%), Other Pacific Islanders (3.3%), Asian (2.8%) Other (2.4)

**GOVERNMENT/ POLITICAL STATUS:** U.S. Territory. American Samoa is an unincorporated and unorganized territory and is administered by the U.S. Department of the Interior. It was relinquished through to the U.S. through deeds of cession in 1900. It is unincorporated because not all provisions of the U.S. Constitution apply to the territory. It is unorganized because U.S. Congress has not provided an organic act, which would provide for the organization of the government and its relationship to the federal government.

**ECONOMY:** American Samoa's economy is heavily dependent on Federal expenditures and 2 tuna canneries. Compromising 93% of the nation's economy, the remaining 7% stems from tourism, garment manufacturing and small businesses. Combined, the American Samoa government and canneries account for 61.5% of the employment in 1994.

**HEALTH ACCESS:** American Samoa has only 1 hospital. Basic preventative health services are delivered through 5 village dispensaries. All HIV/AIDS and general health services are delivered through the Department of Health and the LBJ Tropical Medical Hospital. The Medicare/Medicaid program does provide payment for medical services.

## COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS

**GEOGRAPHIC AREA:** Consists of 14 islands with a total land area of 176.5 square miles. The main islands are Saipan, Rota and Tinian. It is located in the Micronesia region of the Pacific Ocean (*Land area is 2.5 times the size of Washington D.C.*)

**CULTURE:** Chamorros share a common history and culture with the Chamorros of Guam.

Also Carolinians share common histories with the people of the Republic of Palau and FSM.

**LANGUAGES:** Official languages are Chamorro, Carolinian and English.

**POPULATION:** CNMI's population 69,221. (2000 Census)

**ETHNIC DISTRIBUTION:** Chamorros (21.3%), Carolinas (3.8%), other Pacific Islanders (6.7%), Filipinos (26.2%) Japanese, Chinese, Koreans and other Asians (29.6%), Other (2.6%).

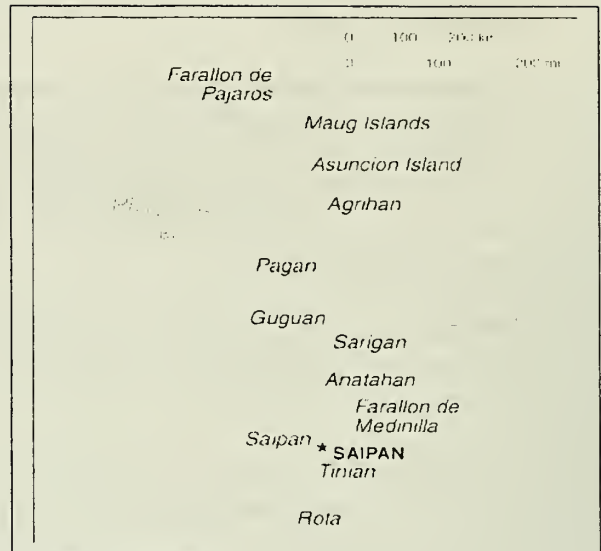
**POLITICAL STATUS/ GOVERNMENT:** U.S. Territory. CNMI is a self-governing Commonwealth of the United States. The people of CNMI voted to join the U.S. in a 1975 act of self-determination and were granted U.S. citizenship in 1986.

**ECONOMY:** CNMI experienced dramatic economic growth over the past decade due to tourism, construction and the garment manufacturing industry.

**INDUSTRIES:** Tourism, construction, garment manufacturing and handicrafts. In CNMI, garment manufacturing thrives on a special exemption that allows CNMI garment factories to export into the United States without quotas or paying a customs duty. In recent years total garment shipments from CNMI to the United States has been steady increasing by more than 40% a year. Temporary workers comprise 69% of the total CNMI workforce in 1996. Tourism has been increasing at an average of 30% per year.

**HEALTH ACCESS:** CNMI's Department of Public Health is the sole provider of comprehensive health services, with the Commonwealth Health center. CNMI has 2 sub-hospitals in Rota and Tinian.

The Medicare/Medicaid program does provide payment for medical services.





## FEDERATED STATES OF MICRONESIA

**GEOGRAPHIC AREA:** Consists of 607 small atolls and islands scattered over a million square miles, but constitutes only 271 square miles of land area. The distance from Kosrae State in the East and Yap state in the west is over 1,700 miles and covers 2 time zones. The country is divided into four island states: Yap, Chuuk, Kosrae and Pohnpei. It is located in the Micronesia region of the Pacific Ocean (*Land area is 4 times the size of Washington D.C.*).

**CULTURE:** The cultures of the FSM are tremendously diverse. Nine separate language with different dialects are spoken throughout the islands.

**LANGUAGES:** Trukese, Pohnpeian, Yapese, Kosrean and English are the official languages.

**POPULATION:** Federated States of Micronesia has a population of 127,616 (2000 est.). (Chuuk; 50,000, Pohnpei; 35,000, Yap; 12,000, and Kosrae; 7,500).

**ETHNIC DISTRIBUTION:** Most of the population is Micronesian. Polynesia, other Pacific Islanders and Asian make up a small percentage.

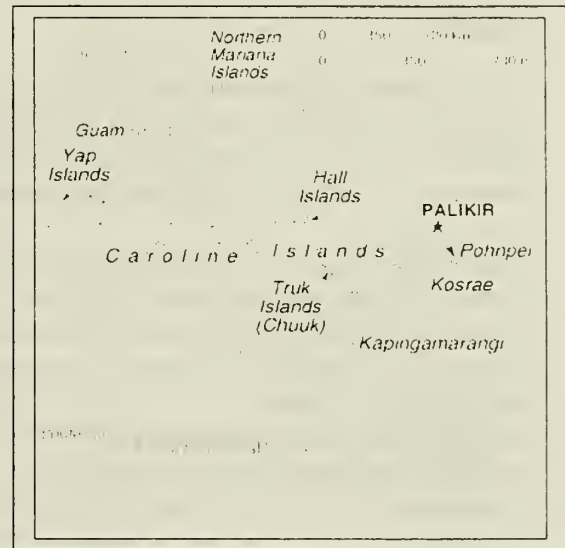
**POLITICAL STATUS/ GOVERNMENT:** FSM is a sovereign, self-governing state in free association with the U.S. The governments of FSM and U.S. signed the final version of the Compacts of Free Association in 1982. Under the Compacts, the status of free association recognized that FSM is a sovereign state with the capacity to conduct foreign affairs consistent with the terms of the Compacts.

**ECONOMY:** Economic activity consists primarily of subsistence farming and fishing. FSM is slowing moving into a monetary economy as the urban centers continue to grow. FSM possesses no significant exploitable natural resources but the ocean, in which FSM claims a large exclusive economic zone that straddles the world's richest tuna fishing grounds.

**INDUSTRIES:** Fishing, fish processing, tourism, construction, handicrafts

**HEALTH ACCESS:** FSM has 4 hospitals plus 82 dispensaries that provide dental services and medical supplies. Each of the 4 states maintains its own health and social service system with overall coordination, guidance and technical assistance by the national office in Pohnpei.

The Medicare/Medicaid program does not provide payment for medical services.



## GUAM

**GEOGRAPHIC AREA:** Consists of a single island of 212 square miles. It is located in the Micronesia region of the Pacific Ocean (*Land area is 3 times the size of Washington D.C.*).

**CULTURE:** Guam has evolved into a multi-ethnic society. Guam has no single ethnic group constituting more than 50% of the population although Chamorros make up the largest ethnic group.

**LANGUAGES:** Chamorro and English are the official language. Other Micronesian languages, Filipino and Japanese are also spoken.



**POPULATION:** The population is 154,805 (2000 Census).

The expanding 2 urban commercial centers are surrounded by suburban sprawl, undeveloped land and small 'family' ranches. The U.S. Census Bureau definitions for rural and urban communities are not appropriate for Guam. Using this definition Guam's capital city of Agana would be considered to be a rural community, while Inarjan, an important agricultural area, would be considered to be urban.

**ETHNIC DISTRIBUTION:** Chamorro (37%), Other Pacific Islander (7.6%) Filipino (26.3%), Other Asian (6.2%) Other (9%)

**POLITICAL STATUS/ GOVERNMENT:** U.S. Territory. Guam is an unincorporated, organized territory of the United States. Guam was annexed, along with Puerto Rico and Hawai'i, after the Spanish-American War in 1898. The people of Guam were made U.S. citizens in 1950.

**ECONOMY:** Guam's economy is based on 2 main sources of revenue - tourism and U.S. military expenditures. Since the 1960s, Guam has been transitioning from the military into a tourism and market base.

**HEALTH ACCESS:** HIV/AIDS Services in Guam are mainly delivered through the Department of Health along with the Southern Region Health Center, Northern Region Health Center and Coral Life Foundation, the region's only community based AIDS organization. There are also general health services through HMOs and private physicians.

Guam is currently the only jurisdiction in the region to offer ADAP to PLWAs, as well as Orasure testing.

The Medicare/Medicaid program does provide payment for medical services.

## REPUBLIC OF THE MARSHALL ISLANDS

**GEOGRAPHIC AREA:** Republic of the Marshall Islands consists of 5 islands and 29 atolls with a total land area of 181.3 square miles that spans a geographic region of 750,000 square miles. RMI is divided into 2 parallel channels: Ratak (Sunrise) Chain and Ralik (Sunset) Chain. It is located in the Micronesia region of the Pacific Ocean. In the Ralik Chain, Ebeye Island, part of the Kwajalein Atoll is the main area of U.S. military test bombing and activities (*Land area is slightly larger than Washington D.C.*).

**PEOPLE/CULTURE:** Marshallese culture revolves around a complex clan system. Traditionally, the sea was a major source of food and a thoroughfare among atolls.

**LANGUAGES:** Marshallese (2 dialects) and English. Marshallese is a dialect of the Malayo-Polynesian family.

**POPULATION:** RMI has a population of 68,126 (2000 est.) with the majority of people concentrated in the 2 urban centers of Majuro and Ebeye.

**ETHNIC DISTRIBUTION:** Marshallese (96.9%), Other Pacific Islanders, Asians and Whites (3.1%)

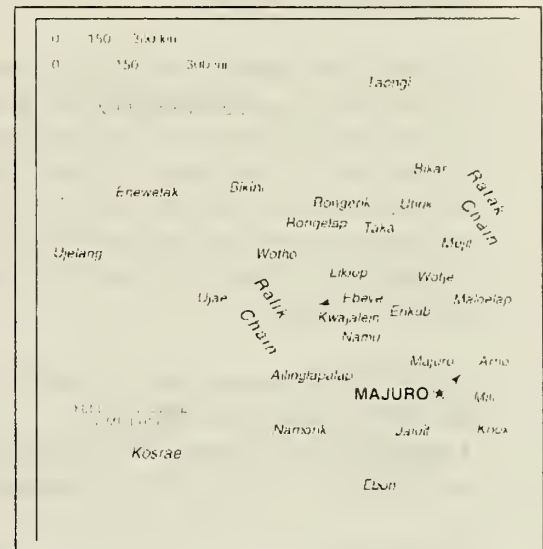
**POLITICAL STATUS/ GOVERNMENT:** RMI is a sovereign, self-governing state in free association with the U.S. RMI and U.S. signed a final version of the Compacts of Free Association in 1983.

An obligation under the Compacts is the leasing of the islands in the Kwajalein Atoll to the U.S. for its military operations. These effects from the military operation, especially the test bombings, has had a significant impact on RMI's health, especially among cancer rates.

**ECONOMY:** RMI is a mixture of subsistence and monetized economy. Major restraints to RMI's economic growth and development are the remoteness from major centers of trade, a small natural resource base and a population dispersed among numerous islands and atolls.

**HEALTH ACCESS:** RMI has 2 hospitals in Majuro and Ebeye, and 60 health centers in the outer atolls. The Department of Health administers and delivers most of the health services.

The Medicare/Medicaid program does not provide payment for medical services.

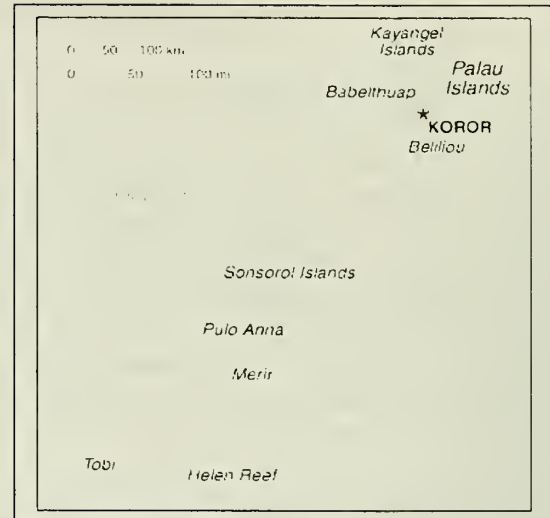


## REPUBLIC OF PALAU

**GEOGRAPHIC AREA:** Republic of Palau is made up of 200 islands stretching into an archipelago over 300 miles long. Palau's total land area is 196.10 square miles. The largest island, Baeldaob, accounts for 151 square miles. It is located in the Micronesia region of the Pacific Ocean (*Land area slightly more than 2.5 times the size of Washington D.C.*)

**CULTURE:** Palauans are Micronesian with Malayan and Melanesian heritage.

**LANGUAGES:** Palauan, Sonsorolese, Tobian, Anguar and English are the official languages.



**POPULATION:** 19,129 (2000 est.), concentrated in Koror, the capital.

**ETHNIC DISTRIBUTION:** Palauans make up the majority with an increasing Asian immigrant population

**POLITICAL STATUS/ GOVERNMENT:** Palau is a sovereign, self-governing state in free association with the U.S.. Palau and U.S. signed a final version of the Compacts of Free Association in 1994.

**ECONOMY:** One of the cornerstone's of Palau's economy is tourism. Since 1997, visitor arrivals have grown steadily (28% increase), with Asia being the main source. Tourism and the accompanying hotel and apartment construction industry are expected to lead Palau's economic growth over the next decade. Palau continues to rely on subsistence agriculture and fishing.

**HEALTH ACCESS:** Palau has 2 private medical clinics and 1 public hospital. HIV/AIDS Services are primarily delivered through the Ministry of Health. The Medicare/Medicaid program does not provide payment for medical services.





## Notes

***Title III Initiative II: Grants to Expand and Enhance Organizational Capacity Building to Provide HIV Early Intervention Services***

The Asian & Pacific Islander American Health Forum (APIAHF), in conjunction with its advisory committee, the Pacific Island Jurisdictions AIDS Action Group (PIJAAG), submits this Title III Capacity-Building Grant proposal to develop, expand, and enhance the Pacific Island Jurisdictions' capacity to provide primary HIV health care.

The Pacific Island Jurisdictions are comprised of three U.S. territories and three U.S. freely associated states. U.S. territories include American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI) and Guam. U.S. freely associated states include the Federated States of Micronesia (FSM), the Republic of the Marshall Islands (RMI), and the Republic of Palau. All are predominately rural communities with a majority Pacific Islander and Asian populations. Availability of power, sewage control, paved roads, water, food and other basic infrastructure needs are continuing issues in many of the Pacific jurisdictions. All jurisdictions have young, sexually active populations, with high rates of STDs and teenage pregnancy. Each jurisdiction is dealing with an influx of tourists and foreign workers. Migration between islands is common. Many islanders travel to and from the continental U.S. Some of the jurisdictions are dealing with increased commercial sex work. However, there are few non-governmental agencies (in all areas of health and social services, including HIV/AIDS) in the Pacific jurisdictions. All the jurisdictions rely on the strengths of their health departments and Ministries of Health. Five of the six jurisdictions are receiving Title II funding for the first time this year.

Given the increased funding for HIV care services in the region, this proposal seeks to develop and implement a coordinated, regional approach to the development of HIV care and early intervention services that would be implemented by each of the six Pacific Island Jurisdictions. APIAHF's organizational history of capacity-building assistance on HIV/AIDS for Asian American and Pacific Islander populations and our effective working relationships with the Department of Health and Human Services makes us uniquely qualified to implement this proposed capacity-building program. APIAHF will continue to rely on the Pacific Island Jurisdictions AIDS Action Group as its community and constituency advisory committee. Similarly, this proposal utilizes the indigenous leadership provided by the Coral Life Foundation, the only AIDS service organization in the Pacific region, and its executive director, Vince Crisostomo, one of the only out PLWHA of Pacific Islander ancestry living in the region.

Following the goals and objectives of the Health Resources and Service Administration (HRSA) Title III program, this proposal will help build the clinical service delivery capacity of the region, through overall regional activities coordination, regional capacity-building assistance, and one-on-one capacity-building with each of the jurisdictions.

- § ***Goal I: Increase coordination and collaboration between the jurisdictions.***
- § ***Goal II: Develop and support HIV training and technical assistance in the region.***
- § ***Goal III: Work with each jurisdiction to develop capacity for baseline standard of HIV care services.***

Objectives include yearly training to increase capacity to serve HIV clients, standardized policies and procedures for the region to ensure client confidentiality and rights, enhancement of each jurisdictions' internal infrastructure to provide services, and the development of a shared medical records system between the jurisdictions. This proposal is coordinated with the Title III Planning Grants each of the six jurisdictions is submitting. Those planning grants will develop local linkages to care services and continue development of their local HIV needs assessment. APIAHF will be working with each jurisdiction to conduct a regional needs assessment and develop a comprehensive model of care in coordination with their planning grant activities.

## PACIFIC ISLAND JURISDICTION REGION

### NUMBER OF TERRITORIES: 3

(American Samoa, Commonwealth of the Northern Mariana Islands, Guam)

### NUMBER OF FREELY ASSOCIATED STATES: 3

(Federated States of Micronesia, Republic of the Marshall Islands, Republic of Palau)

**COMBINED POPULATION:** 519, 897

**REGION'S AVERAGE GROWTH RATE:** 4.73%

**AVERAGE U.S. GROWTH RATE:** 0.91%

**REGION'S AVERAGE LIFE EXPECTANCY:** 70 years

**AVERAGE U.S. LIFE EXPECTANCY:** 76 years

### HEALTH CARE ACCESS:

Medicaid/ Medicare is ONLY available for the U.S. territories.

Medicaid/ Medicare is NOT available in the freely associate states.

**TRANSPORTATION** Over 20% of the region's residents must travel for over 1 HOUR to a health facility.

**OFF ISLAND REFERRALS:** 20-30% of American Samoa and RMI's health care budgets were spent on off-island referrals.

**NUMBER OF AIDS CASES, 1999:** 10

**IN 1998:** 11

**NUMBER OF KNOWN HIV CASES:** 98

**PROJECTED NUMBER:** 860

**NUMBER OF GONORRHEA CASES, 1999:** 462

**IN 1998:** 448

**NUMBER OF SYPHILIS CASES, 1999:** 201+

**IN 1998:** 330+

**COMMON ECONOMIC TRENDS:** Shifting for a subsistence farming and fishing to money/market economy. Military expenditures are dropping but still prominent.

**DOMINANT INDUSTRIES:** Tourism, construction, fishing, fish processing, garment manufacturing, military.

**AVERAGE GDP - PER CAPITA INCOME:** \$7,301.50. Guam has the highest (\$19,000) and RMI has the lowest (\$1,670)

**COMMUNICATION:** Commonwealth of the Northern Mariana Islands and Guam was integrated into the North American Telephone Numbering Plan in 1997, which allows domestic calling.

American Samoa, FSM, Palau and RMI require international calling.

**LONG DISTANCE PHONE RATES:** Range from \$2.50 - \$5.00 a minute.

## Background about the Pacific Island Jurisdictions

### GENERAL

The Pacific Island Jurisdictions are comprised of three U.S. territories and three U.S. freely associated states. U.S. territories include American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI) and Guam. U.S. freely associated states include the Federated States of Micronesia (FSM), the Republic of the Marshall Islands (RMI), and the Republic of Palau.

Contemporary histories of the Pacific Island Jurisdictions are complex, with legacies of colonization by Spain, Germany, Japan, as well as the U.S. The current U.S. involvement in the region is equally complicated; issues of self determination, land rights, federal dependency, U.S. military presence, nuclear weapons testing and related illnesses, immigration policies, and labor conditions continue to dominate this relationship.

Some basic information about the Pacific Island Jurisdictions:

- ξ All are predominately rural island communities, primarily organized by villages. Each jurisdiction has urban centers, though, which draw people in search of jobs and education.
- ξ The jurisdictions all have majority Pacific Islander and Asian populations.
- ξ The jurisdictions are very small. The largest, FSM, at 270 square miles (not all of which is inhabitable) is smaller than the state of Rhode Island. However, it occupies more than one million square miles of the Pacific Ocean and ranges 1,700 miles from East (Kosrae) to West (Yap) (*Office of the Insular Affairs State of the Islands Report 1999*).
- ξ While English is the language most commonly used in government business, English is not the language commonly spoken at home in any of the jurisdictions (*OIA Report 1999*).
- ξ Each island has very distinct populations, geographies, cultures, languages, and economies. For example, Guam has one of the largest populations (154,623) on a single island, with \$19,000 per capita annual income; the Republic of Marshall Islands has a small population (68,126) spread out on 31 atolls, with \$1,670 per capita annual income (*Central Intelligence Agency World Factbook 2000*).
- ξ Availability of power, sewage control, paved roads, water, food and other basic infrastructure needs are on-going issues in many of the Pacific jurisdictions. Natural disasters (typhoons, cyclones, earthquakes, and tsunami) have continued to devastate the region and directly affect the region's access to reliable basic necessities.



## AMERICAN SAMOA

**GEOGRAPHIC AREA:** American Samoa is made up of 7 islands with a total land area of 76 square miles dispersed over 150 miles. It is the only jurisdiction in the Polynesia region of the Pacific Ocean.

**AREA COMPARATIVE:** Land area is slightly larger than Washington, D.C.

**PEOPLE:** American Samoans, together with Native Hawaiians, Maoris, Tongans and Tahitians are Polynesians.

**CULTURE:** *Fa'a*, meaning the Samoan way of life, has kept Samoans conscious of their ethnic traditions and flexible to withstand changes brought by foreign trade, military forces and missionaries. Samoan life revolves around the *aiga*, the extended family.

**LANGUAGES:** Official languages are Samoan and English.

**POPULATION:** American Samoa has a population 65,446 with 95% of the total population living in the urban center on the island of Tutuila.

**GROWTH RATE:** 2.53% (2000 est.)

**ETHNIC DISTRIBUTION:** Samoan (89%), Tongan (4%), Fijian, Tahitian and other (7%)

**LIFE EXPECTANCY:** 72 years

**GOVERNMENT/ POLITICAL STATUS:** U.S.

Territory. American Samoa is an unincorporated and unorganized territory and is administered by the U.S. Department of the Interior. It was relinquished through to the U.S. through deeds of cession in 1900. It is unincorporated because not all provisions of the U.S. Constitution apply to the territory. It is unorganized because U.S. Congress has not provided an organic act, which would provide for the organization of the government and its relationship to the federal government.

**ECONOMY:** Compromising 93% of the nation's economy, American Samoa's economy is heavily dependent on Federal expenditures and 2 tuna canneries. The remaining 7% stems from tourism, garment manufacturing and small businesses. Combined, the American Samoa government and canneries account for 61.5% of the employment in 1994.

**GDP:** \$150 million (1995 est.)

**GDP – PER CAPITA INCOME:** \$3,039 (1995 est.)

**UNEMPLOYMENT RATE:** 12% (1991)

**INDUSTRIES:** Government, canneries, tourism and small business.

**HEALTH ACCESS:** American Samoa has only 1 hospital. Basic preventative health services are delivered through 5 village dispensaries. All HIV and general health services are delivered through the Department of Health and the LBJ Tropical Medical Hospital.

Medicare/Medicaid program does provide payment of medical services.

- ξ Time zones and datelines vary greatly in the jurisdictions. For example, 4:00pm on Wednesday in San Francisco (7:00pm in Washington, DC; 1:00pm in Hawai'i), is 12:00pm on Wednesday in American Samoa, 9:00am on Thursday in Commonwealth of the Northern Mariana Islands, 10:00am on Thursday in Federated States of Micronesia, 9:00am on Thursday in Guam, 11:00am on Thursday in the Republic of the Marshall Islands, and 8:00am on Thursday in Palau.
- ξ Travel to San Francisco, the closest U.S. continental city, can take on average 20 hours. There are no direct flights. Monopolies in telecommunications and air travel have further isolated these island nations.
- ξ All jurisdictions have young populations. In comparison to the 1995 median age of 33.6 years in the U.S., the jurisdictions ranged from 28.1 years in Palau to 16.2 year in RMI (*OIA Report 1999*).
- ξ Each jurisdiction is dealing with an influx of tourists. In 1996, Guam had 1,362,000 tourists visit; CNMI had 736,000; and Palau had 70,000.
- ξ Migration between islands is common, for historical, cultural, and economic reasons. The Compact of Free Association Act of 1988, which establishes the relationship between the U.S. and FSM and RMI, authorized immigration of FSM and RMI citizens into the U.S., its territories, and possessions. This has had significant impact on migration in the region. For example, preliminary results of Guam's 1997 census show that Guam's resident population from these nations has increase by about 4,568 persons since implementation of the Compact (*OIA Report 1999*). In addition, many Pacific Islanders travel to and from the continental U.S. and Hawai'i.
- ξ The jurisdictions have an influx of Asian foreign workers, coming primarily from China, Korea, Philippines, and Thailand. For example, the 1999 population of CNMI (79,000) has increased about 82% since 1980; most of this increase attributed for by non-resident workers and their families (*OIA Factsheet 2000*).
- ξ Economies range from subsistence economies to money economies.
- ξ There are few non-governmental agencies (in all areas of health and social services, including HIV/AIDS) in the Pacific jurisdictions. All the jurisdictions rely on the strengths of their health departments, hospitals, and Ministries of Health for the majority of their health care and social service needs.
- ξ Five of the six jurisdictions are receiving Title II funding for the first time this year.

## COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS

**GEOGRAPHIC AREA:** Commonwealth of the Northern Mariana Islands consists of 14 islands with a total land area of 176.5 square miles. The main islands are Saipan, Rota and Tinian. It is located in the Micronesia region of the Pacific Ocean.

**AREA COMPARATIVE:** Land area is 2.5 times the size of Washington D.C.

### PEOPLE

**CULTURE:** Chamorros share a common history and culture with the Chamorros of Guam. Also Carolinians share common histories with the people of the Republic of Palau and FSM.

**LANGUAGES:** Official languages are Chamorro, Carolinian and English. 86% of the population speaks a language other than English at home.

**POPULATION:** CNMI's population in 1998 is estimated to be about 79,429.

**GROWTH RATE:** 3.75% (2000 est.)

**LIFE EXPECTANCY:** 68 years

**MEDIAN AGE:** 17.2 years

**ETHNIC DISTRIBUTION:** Chamorros (31%), Carolinas (7%), other Micronesians (7%), Filipinos (33%) Japanese, Chinese, Koreans and other Asians (19%), Other (3%).

### POLITICAL STATUS/ GOVERNMENT:

U.S. Territory. CNMI is a self-governing Commonwealth of the United States. The people of CNMI voted to join the U.S. in a 1975 act of self-determination and were granted U.S. citizenship in 1986.

**ECONOMY:** CNMI experienced dramatic economic growth over the past decade due to tourism, construction and the garment manufacturing industry.

**GDP:** \$524 million (1996 est.)

**GDP - PER CAPITA INCOME:** \$9,300 (1996 est.)

**UNEMPLOYMENT RATE:** 14%

**INDUSTRIES:** Tourism, construction, garment manufacturing and handicrafts

In CNMI, garment manufacturing thrives on a special exemption that allows CNMI garment factories to export into the United States without quotas or paying a customs duty. In recent years total garment shipments from CNMI to the United States has been steady increasing by more than 40% a year. Temporary workers comprise 69% of the total CNMI workforce in 1996. Tourism has been increasing at an average of 30% per year.

**HEALTH ACCESS:** CNMI's Department of Public Health is the sole provider of comprehensive health services, with the Commonwealth Health center. CNMI has 2 sub-hospitals in Rota and Tinian. Medicare/Medicaid program does provide payment of medical services.

## Background on the Pacific Island Jurisdictions AIDS Action Group (PIJAAG)

In February 2001, representatives from five of the six Pacific Island Jurisdictions (American Samoa, CNMI, FSM, Guam, and Republic of Palau) met for five days in Honolulu, Hawai'i to discuss the state of HIV prevention and care services in their respective jurisdictions. This group, which included AIDS directors, program staff, community stakeholders, as well as capacity-building assistance providers like Asian & Pacific Islander American Health Forum (APIAHF), discussed the shared experiences of the jurisdictions and began development of a regional approach to the epidemic. The group has met twice since that initial meeting; in March 2001 at the *Community Planning Leadership Summit* in Houston, Texas and then in April 2001 at APIAHF's *VOICES from the Community Conference* in San Francisco, California.

As a result of these meetings, the Pacific Island Jurisdictions AIDS Action Group (PIJAAG) formed to advance this regional plan.

### PIJAAG MISSION STATEMENT

*We are representatives of the United States affiliated Pacific Island Jurisdictions standing united to speak in one voice around the shared issues of HIV/AIDS in our island communities.*

- ξ *We advocate for the provision of quality HIV prevention and care services in the region.*
- ξ *We advise national, international, and local policy entities on HIV/AIDS.*
- ξ *We strengthen and coordinate AIDS activities through the sharing of information and resources within the region.*

PIJAAG strongly advocates for changes in the response to the AIDS epidemic in the Pacific region, both internally as a region and externally from federal agencies like the Centers for Disease Control & Prevention (CDC) and Health Resources and Services Administration (HRSA). A regional model of HIV prevention and services needs to be developed. PIJAAG is submitting seven recommendations to CDC for consideration and further discussion on HIV prevention in the region. PIJAAG also has been successful in advocating with the Pacific Island Health Officers Association (PIHOA) to support PIJAAG (*See PIHOA Letter of Support*). PIHOA is the association of Health Ministers and Department of Health directors in the Pacific. Through PIJAAG members' urging, PIHOA made HIV/AIDS in the Pacific the focus of their Spring 2002 meeting, with a scheduled presentation by PIJAAG. PIJAAG continues to support the increase in collaboration between the jurisdictions, most recently through the April meeting case conferencing session on migrating clients in the region. In this session, the jurisdictions had opportunities to discuss strategies on specific cases that pertained to multiple jurisdictions, given the



## FEDERATED STATES OF MICRONESIA

**GEOGRAPHIC AREA:** Federated States of Micronesia is an island nation consisting of 607 small atolls and islands scattered over a million square miles, but constitutes only 271 square miles of land area. The distance from Kosrae State in the East and Yap state in the west is over 1,700 miles and covers 2 time zones. The country is divided into four island states: Yap, Chuuk, Kosrae and Pohnpei. It is located in the Micronesia region of the Pacific Ocean.

**AREA COMPARATIVE:** land area is 4 times the size of Washington D.C.

### PEOPLE

**CULTURE:** The cultures of the FSM are tremendously diverse. Nine separate language with different dialects are spoken throughout the islands.

**LANGUAGES:** Trukese, Pohnpeian, Yapese, Kosraean and English are the official languages.

**POPULATION:** Federated States of Micronesia has a population of 127,616 (2000 est.). (Chuuk; 50,000, Pohnpei; 35,000, Yap; 12,000, and Kosrae; 7,500).

**GROWTH RATE:** 3.28% (2000 est.)

**ETHNIC DISTRIBUTION:** Most of the population is Micronesian. Polynesia, other Pacific Islanders and Asian make up a small percentage.

**LIFE EXPECTANCY:** 68.3 years

**POLITICAL STATUS/ GOVERNMENT:** FSM is a sovereign, self-governing state in free association with the U.S. The governments of FSM and U.S. signed the final version of the Compacts of Free Association in 1982. Under the Compacts, the status of free association recognized that FSM is a sovereign state with the capacity to conduct foreign affairs consistent with the terms of the Compacts.

**ECONOMY:** Economic activity consists primarily of subsistence farming and fishing. FSM is slowly moving into a monetary economy as the urban centers continue to grow. FSM possesses no significant exploitable natural resources but the ocean, in which FSM claims a large exclusive economic zone that straddles the world's richest tuna fishing grounds.

**GDP:** \$240 million (1997 est.)

**GDP - PER CAPITA INCOME:** \$2,000 (1997 est.)

**UNEMPLOYMENT RATE:** 27%

**INDUSTRIES:** Fishing, fish processing, tourism, construction, handicrafts

**HEALTH ACCESS:** FSM has 4 hospitals and 82 dispensaries as well as to provide dental services and medical supplies. Each of the 4 states maintains its own health and social service system with overall coordination, guidance and technical assistance by the national office in Pohnpei. Medicare/Medicaid program does not provide payment of medical services.

migration of the clients. Issues of confidentiality, policies and procedures, and the uneven availability of services were discussed. The discussion also brought forward provocative approaches to address these issues, such as a shared medical records system and regional case management, as well as continuing case conferencing, so a PLWHA's experience getting services is easier and more efficient throughout the region.

PIJAAG has also been instrumental in the advocacy for Pacific Island Jurisdictions with the National Alliance of State and Territorial AIDS Directors (NASTAD), with two PIJAAG members attending the April NASTAD annual AIDS directors meeting to advocate for a greater NASTAD role in the Pacific. In addition, PIJAAG has met three times with HRSA representatives, both with HIV/AIDS Bureau and Region IX staff to discuss developing and strengthening HIV care services in the jurisdictions, from local and regional perspectives. From these meetings, the Pacific Islander Jurisdictions strategized submissions for Title II funds (five for the first time); all were successful in their applications. Finally, from these meetings this collaborative regional Title III grant was also developed, working in conjunction with each jurisdiction's Title II award and Title III planning grant applications.

APIAHF has worked with PIJAAG from the beginning, convening the first meeting in Honolulu, and continued support of the development of the group through its on-going participation as a capacity-building assistance provider. At PIJAAG's request, APIAHF is submitting this grant application to further build the regions' capacity to provide a continuum of HIV services. PIJAAG will serve as the advisory committee for this project. APIAHF will continue to provide support through its national capacity-building assistance program and working relationships with the Department of Health and Human Services and other capacity-building assistance providers. Coral Life Foundation, as the only AIDS service organization in the Pacific Island Jurisdictions, will provide regional coordination for this project.

Following the goals and objectives of the HRSA Title III program, this proposal will help build the clinical service delivery capacity of the region, through overall regional activities coordination, regional capacity-building assistance, and one-on-one capacity-building with each of the jurisdictions.

\* APIAHF's work with PIJAAG continues relationships developed with the jurisdictions through CDC prevention capacity-building assistance programs. During APIAHF's first *VOICES from the Community Conference* in 1997, APIAHF convened a Pacific Island Jurisdiction workshop on HIV/AIDS. In 1998, APIAHF, with other Capacity-Building Assistance Providers, CDC, and the Guam Department of Health convened a training for all of the jurisdictions, *HIV Prevention in the Pacific: A Technical Assistance & Training Workshop*. Follow-up from that meeting included a Counseling Testing Referral and Partner Notification training in 1999 and the *Hawai'i Community Planning Leadership Orientation Training* in 2001.

## GUAM

**GEOGRAPHIC AREA:** Guam consists of a single island of 212 square miles. It is located in the Micronesia region of the Pacific Ocean.

**AREA COMPARATIVE:** land area is 3 times the size of Washington D.C.

### PEOPLE

**CULTURE:** Guam has evolved into a multi-ethnic society. Guam has no single ethnic group constituting more than 50% of the population although Chamorros make up the largest ethnic group.

**LANGUAGES:** Chamorro and English are the official language. Other Micronesian languages, Filipino and Japanese are also spoken.

**POPULATION:** The population is estimated to be 154,623 (2000 est.). The expanding 2 urban commercial centers are surrounded by suburban sprawl, undeveloped land and small 'family' ranches. The U.S. Census Bureau definitions for rural and urban communities are not appropriate for Guam. Using this definition Guam's capital city of Agaña would be considered to be a rural community, while Inarjan, an important agricultural area, would be considered to be urban.

**GROWTH RATE:** 1.9% (2000 est.)

**ETHNIC DISTRIBUTION:** Chamorro (47%), Filipino (25%), White (10%), Chinese, Japanese, Korean and other (18%)

**LIFE EXPECTANCY:** 77.78 years

### POLITICAL STATUS/ GOVERNMENT:

U.S. Territory. Guam is an unincorporated, organized territory of the United States. Guam was annexed, along with Puerto Rico and Hawai'i, after the Spanish-American War in 1898. The people of Guam were made U.S. citizens in 1950.

**ECONOMY:** Guam's economy is based on 2 main sources of revenue - tourism and U.S. military expenditures. Since the 1960s, Guam has been transitioning from the military into a tourism and market base.

**GDP:** \$3 billion (1996 est.)

**GDP - PER CAPITA INCOME:** \$19,000 (1996 est.)

**UNEMPLOYMENT RATE:** 2%

**INDUSTRIES:** U.S. military, tourism, construction, transship services

**HEALTH ACCESS:** HIV / AIDS Services in Guam are mainly delivered through the Department of Health along with the Southern Region Health Center, Northern Region Health Center and Coral Life Foundation, the region's only community based AIDS organization. There are also general health services through HMOs and private physicians.

Guam is currently the only jurisdiction in the region to offer ADAP to PLWAs, as well as Orasure testing.

Medicare/Medicaid program does provide payment of medical services.

## Needs Assessment

### OVERVIEW OF THE ISSUES REGARDING HIV AND AIDS CASES IN THE REGION

Though there are only a few reported cases of HIV/AIDS in the region to date, the Pacific jurisdictions have several factors that emphasize the need for a comprehensive continuum of HIV prevention and services in each jurisdiction and coordinated HIV services in the region: high rates of STDs implying a sexually active population and surrogate marker for HIV infections and high projections of HIV in the region relative to population size.

The following HIV, AIDS, and STD statistics are compiled from various sources. The HIV and AIDS cases come from the jurisdictions themselves, not the "official" CDC reported cases, which, through December 2000 had 46 cumulative AIDS cases in Guam and 2 cases in the rest of the Pacific Island Jurisdictions. At the August 1999 Counseling Testing Referral Partner Notification training held specifically for the jurisdictions, CDC discovered that HIV cases reported from the jurisdictions had not reached the CDC Surveillance branch. CDC is currently investigating these discrepancies. In the meantime, the jurisdictions have reported their updated cases in both their CDC 2000 Prevention applications as well as their HRSA Title II applications. These on-going issues regarding surveillance again highlight the need for prioritized attention.

Given the relatively small population sizes of the jurisdictions, rates when given are calculated per 1,000 instead of 100,000.

Rates are based on the following population data:

American Samoa: 65,446 (CIA 2000 estimate)

CNMI: 79,429 (Department of Commerce/Division of Statistics)

FSM: 133,144 (CIA 2000 estimates)

Guam: 154,623 (CIA 2000 estimates)

RMI: 68,126 (CIA 2000 estimates)

Republic of Palau: 19,129 (Republic of Palau 2000 census)

### HIV and AIDS

JURISDICTION	AIDS 1998	AIDS 1999	AIDS 2000	AIDS cumulative.
American Samoa	0	0	0	0
Commonwealth of the Northern Mariana Islands	2	1	1	16
Federated States of Micronesia	1	0	1	4
Guam	8	8	7	59
Republic of the Marshall Islands	0	0	0	2
Republic of Palau	0	1	0	2
<b>TOTAL FOR REGION</b>	<b>11</b>	<b>10</b>	<b>9</b>	<b>83</b>



## REPUBLIC OF THE MARSHALL ISLANDS

**GEOGRAPHIC AREA:** Republic of the Marshall Islands consists of 5 islands and 29 atolls with a total land area of 181.3 square miles that spans a geographic region of 750,000 square miles. RMI is divided into 2 parallel channels: Ratak (Sunrise) Chain and Ralik (Sunset) Chain. It is located in the Micronesia region of the Pacific Ocean. In the Ralik Chain, Ebeye Island, part of the Kwajalein Atoll is the main area of U.S. military test bombing and activities.

**AREA COMPARATIVE:** slightly larger than Washington D.C.

**PEOPLE/CULTURE:** Marshallese culture revolves around a complex clan system. Traditionally, the sea was a major source of food and a thoroughfare among atolls.

**LANGUAGES:** Marshallese (2 dialects) and English. Marshallese is a dialect of the Malayo-Polynesian family.

**POPULATION:** RMI has a population of 68,126 (2000 est.) with the majority of people concentrated in the 2 urban centers of Majuro and Ebeye.

**GROWTH RATE:** 3.88% (2000 est.)

**ETHNIC DISTRIBUTION:** Marshallese (96.9%), Other Pacific Islanders, Asians and Whites (3.1%)

**LIFE EXPECTANCY:** 65.5 years

**MEDIAN AGE:** 16.2 years

**POLITICAL STATUS/ GOVERNMENT:** RMI is a sovereign, self-governing state in free association with the U.S. RMI and U.S. signed a final version of the Compacts of Free Association in 1983.

An obligation under the Compacts is the leasing of the islands in the Kwajalein Atoll to the U.S. for its military operations. These effects from the military operation, especially the test bombings, has had a significant impact on RMI's health, especially among cancer rates.

**ECONOMY:** RMI is a mixture of subsistence and monetized economy. Major restraint facing RMI's economic growth and development are the remoteness from major centers of trade, a small natural resource base and a population dispersed among numerous islands and atolls.

**GDP:** \$105 million (1998 est.)

**GDP - PER CAPITA INCOME:** \$1,670 (1998 est.)

**UNEMPLOYMENT RATE:** 16%

**INDUSTRIES:** Copra, fishing, tourism, and handicrafts

**INFRASTRUCTURE/WATER:** Source: Rain catchment (42%), Inside piped water (29.3%), outside piped water (20.6%)

**HEALTH ACCESS:** RMI has 2 hospitals in Majuro and Ebeye, and 60 health centers in the outer atolls. The Department of Health administers and delivers most of the health services.

Medicare/Medicaid program does not provide payment of medical services.

JURISDICTION	HIV known in area	HIV cumulative reported	HIV projected
American Samoa	1 or 0 01/1,000	1	Not available
Commonwealth of the Northern Mariana Islands	10 or 0 13/1,000	38	320 or 4 03/1,000
Federated States of Micronesia	8 or 0 06/1,000	11	90 or 0 68/1,000
Guam	77 or 0 50/1,000	131	450 or 2 91/1,000
Republic of the Marshall Islands	Not available	9	Not available
Republic of Palau	2 or 0 10/1,000	2	No official projections
<b>TOTAL FOR REGION</b>	<b>98+</b>	<b>192</b>	<b>860+</b>

Sources: DPH / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau. Additional information from PAETC 2000 Report, OIA 1999 Report, OIA Fact Sheets, CIA World Factbook 2000, AusAIDS Strategic Plan, and Title II Applications / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau.

The subpopulations at highest risk for HIV/AIDS varies in each jurisdiction. In Guam, for example, Men having Sex with Men (MSM) continue to be the group at highest risk for HIV/AIDS, comprising 70% of HIV cases and 63% of AIDS cases in 1999. Both injecting drug users and heterosexual men and women accounted for 10% of new HIV cases (*Guam Title II application*). While historically MSM were the highest risk group in CNMI, the epidemiology has been changing to include women, teenagers, and newborn babies. Cumulatively, heterosexual men comprise 29% and heterosexual women comprise 29% of the HIV cases in CNMI (*CNMI Title II application*). Most of FSM's HIV/AIDS cases are among the male population (*FSM Title II application*).

HIV/AIDS cases in the jurisdictions are primarily in Pacific Islander and Asian populations. 1999 AIDS cases in Guam shows that 72% of the cases are Pacific Islander or Asian; this population also accounts for 60% of HIV cases that year. In 2000, Guam's seven new cases include five Chamorro/Guamanian and two FSM citizens. CNMI's cumulative HIV/AIDS cases through 2000 indicates that 95% of PLWHA are Pacific Islanders or Asians.

In CNMI, foreign workers must submit to health screenings including HIV testing. Between 1998 and 1999, 6 cases have been reported among workers from the Philippines (0.46/1,000), 4 cases among workers from China (0.27/1,000), and 5 cases among workers from Thailand (8.43/1,000) (*CNMI Title II application*).

The numbers of HIV reported cases do not show the true number of cases of HIV in the jurisdictions and the extent of HIV services burden on the jurisdictions. People may test HIV positive off island but later return home for services. This may be especially true for Pacific Islanders, where cultural and linguistic, as well as familial

## REPUBLIC OF PALAU

**GEOGRAPHIC AREA:** Republic of Palau is made up of 200 islands stretching into an archipelago over 300 miles long. Palau's total land area is 196.10 square miles. The largest island, Babeldaob, accounts for 151 square miles. It is located in the Micronesia region of the Pacific Ocean.

**AREA COMPARATIVE:** land area slightly more than 2.5 times the size of Washington D.C.

### PEOPLE

**CULTURE:** Palauans are Micronesian with Malayan and Melanesian heritage.

**LANGUAGES:** Palauan, Sonsorolese, Tobi, Angwar and English are the official languages.

**POPULATION:** 19,129 (2000 est.), concentrated in Koror, the capital.

**GROWTH RATE:** 1.75% (2000 est.). Palau's population is growing rapidly as a result of foreign in-migration. The demand for foreign labor, especially from Asia, will increase substantially in 2000-2005 period due to the projected demands of the construction industry and tourism industry.

**ETHNIC DISTRIBUTION:** Palauans make up the majority with a rising Asian immigrant population.

**LIFE EXPECTANCY:** 68.47 years

**MEDIAN AGE:** 28.1 years

**POLITICAL STATUS/ GOVERNMENT:** Palau is a sovereign, self-governing state in free association with the U.S.. Palau and U.S. signed a final version of the Compacts of Free Association in 1994.

**ECONOMY:** One of the cornerstones of Palau's economy is tourism. Since 1997, visitor arrivals have grown steadily (28% increase), with Asia being the main source. Tourism and the accompanying hotel and apartment construction industry are expected to lead Palau's economic growth over the next decade. Palau continues to rely on subsistence agriculture and fishing.

**GDP:** \$160 million (1997 est.)

**GDP - PER CAPITA INCOME:** \$8,800 (1997 est.)

**UNEMPLOYMENT RATE:** 7%

**INDUSTRIES:** Tourism, fishing, construction, garment manufacturing, handicrafts

**HEALTH ACCESS:** Palau has 2 private medical clinics and 1 public hospital. HIV/AIDS Services are primarily delivered through the Ministry of Health. The U.S. Medicare/Medicaid program does not provide payment of medical services.

ties, bring many People Living With HIV/AIDS (PLWHA) home when they become sick and require care (*Pacific AIDS Education & Training Report 2000*). For example, in American Samoa, six PLWHA, not tested in the islands, came to American Samoa with end-stage AIDS (*PAETC report 2000*). However, this is not reported as AIDS cases in American Samoa and officially, the island has "zero" AIDS cases. The HIV projections may be a more accurate way to describe the potential burden of care each jurisdiction will face.

Pacific Islanders may also be testing elsewhere because of the lack of confidentiality available for HIV testing. "In most jurisdictions, despite some efforts to the contrary, there is little protection of patient's confidentiality and everyone knows who is being treated for any disease - including HIV..." (*PAETC Report 2000*).

Lack of HIV testing capacity also may deter people from testing in the jurisdictions. If HIV testing is available, it can take 4-6 weeks to get test results in some jurisdictions, because lab work must be sent off island, usually to Hawai'i or Australia (*PIJAAG February meeting*).

Pacific Islanders may test off island because of the lack of HIV care services in the jurisdictions. Five of the six jurisdictions are receiving Title II funds for the first time this year. Even Guam, with the most developed HIV service delivery system in the region, has no case management and "...does not have a continuum of HIV care services" (*Guam Title II application*). Without services available, there is little incentive to test.

## SYPHILIS AND GONORRHEA

JURISDICTION	Syphilis 1998	Syphilis 1999	Gonorrhea 1998	Gonorrhea 1999
American Samoa	2 or 0 03/1,000	5 or 0 08/1,000	13 or 0 20/1,000	16 or 0 24/1,000
Commonwealth of the Northern Mariana Islands	214 or 2 69/1,000	97 or 1 22/1,000	41 or 0 52/1,000	29 or 0 37/1,000
Federated States of Micronesia	Not available	Not available	180 or 1 35/1,000	238 or 1 79/1,000
Guam	7 or 0 05/1,000	9 or 0 06/1,000	73 or 0 47/1,000	55 or 0 36/1,000
Republic of the Marshall Islands	91 or 1 34/1,000	72 or 1 06/1,000	26 or 0 38/1,000	88 or 1 29/1,000
Republic of Palau	16 or 0 84/1,000	18 or 0 94/1,000	115 or 6 01/1,000	36 or 1 88/1,000
<b>TOTAL FOR REGION</b>	<b>330+</b>	<b>201+</b>	<b>448</b>	<b>462</b>

Sources: DPH / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau. Additional information from PAETC 2000 Report, OIA 1999 Report, OIA Fact Sheets, CIA World Factbook 2000, AusAIDS Strategic Plan, and Title II Applications / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau.



These numbers show a high rate of surrogate markers for HIV infection in the region. For example, gonorrhea rates are extremely high in the Republic of Palau; its 1999 rate (1.88/1,000) is higher than the U.S. population rates for whites (0.28/1,000), Hispanics (0.75/1,000), American Indians/Alaska Natives (1.11/1,000) and Asians & Pacific Islanders overall (0.22/1,000). This is also true for the 1999 rates of gonorrhea in FSM (1.79/1,000) and RMI (1.29/1,000). All jurisdictions have rates higher than rates overall for Asians & Pacific Islanders and whites. 1999 syphilis rates in CNMI (1.22/1,000) and RMI (1.06/1,000) are similarly high, compared to the total rate in the U.S. (0.03/1,000) (*Tracking the Hidden Epidemics 2000: Trends in STDs in the United States / CDC*).

Other STD rates, such as Chlamydia, are also extremely high in some of the jurisdictions, for example in RMI (0.54/1,000), Guam (0.30/1,000), and Palau (0.31/1,000). Guam's Chlamydia incidences rates by ethnicity showed Chuukese and others of FSM ancestry had the highest incidence.

These rates imply sexually active populations with unprotected sex and multiple sexual partners. These conclusions are consistent with the 1997 Youth Risk Behavior Survey (CNMI), where 57% of students surveyed have had sex by the 12<sup>th</sup> grade and 80% of sexually active teenagers surveyed don't use any contraception. Anecdotal information from Coral Life Foundation states that in a recent syphilis outbreak this year, 4 of the men were also PLWHA, further suggesting the possibility of HIV transmission. Through focus groups conducted in 2000 by the HIV Prevention Program in Palau, a comprehensive STD/HIV/AIDS needs assessment found that multiple partners and extra-marital sexual relations remain very common among men. The assessment also found that many Palauan men are customers of local commercial sex workers and that safe sex is far from universal within this industry (*Palau Title II application*).

### **Socio-demographic Information**

There are several socio-demographic factors that emphasize the need for a comprehensive continuum of HIV prevention and services in the region.

The six jurisdictions vary in their territorial span of the Pacific Ocean as well as their land mass. For example, Guam consists of a single island and its territory spans 212 square miles while FSM consists of 607 atolls and islands that spans a geographic region of 1,000,000 square miles. This great distance within and between jurisdictions has always been an obstacle to trade, mobility, and has created many barriers related to transportation, communication, commerce, development, and healthcare delivery services, including HIV/AIDS services.

All jurisdictions are predominately rural island communities, primarily organized by villages. Each jurisdiction has 1 or 2 urban centers in which the majority of the population is concentrated and continues to draw people from outlying areas and other islands seeking wage earning employment, access to better education, medical care services and different amenities of urban life. Isolation and barriers to services occurs with communities in outlying islands, as well as with migrating communities adjusting to urban life with diverse populations

#### **POPULATION DEMOGRAPHICS: DISTRIBUTION, MIGRATION AND GROWTH TRENDS**

The Pacific Island jurisdictions have relatively small, but with rapidly growing populations, often spread over several islands and over large expanses of water. Each island has very distinct populations and communities, geographies, languages and economies. For example, Guam has one of the largest populations (154,623) on a single island and American Samoa has one of the smallest populations (65,446) spread over 7 islands (*CIA Fact Book, 2000*).

Migration between the Pacific Island jurisdictions, to Hawai'i and the continental U.S., and from Asia is very common for historical, cultural and economic reasons. As territories, American Samoa, CNMI and Guam nationals are U.S. citizens and can travel to and from the U.S. and its territories without

restrictions. The Compacts of Free Association Act of 1988, which establishes the relationship between the U.S. and FSM and RMI, authorized immigration of FSM and RMI citizens into the U.S., its territories, and possessions. Since this Compacts, the rise in populations such as in Guam has increased by about 4,568 persons (*OIA Report, 1999*). Rapid growth due to immigration and a diversifying population is occurring in all jurisdictions:

- ξ American Samoa's population is rapidly growing an estimate rate of 29% since 1990 Census, despite a large out migration of Samoans to Hawai'i and the continental U.S. (an out-migration trend of about 382 migrants per year since 1974). This growth is a result of in-migration from other islands and high birth rates to residents and non-residents (*OIA Report, 1999*).
- ξ Palau and CNMI have experienced rapid growth in workers from Asia who are contracted to work in the construction industry, tourism, and the garment manufacturing industry. CNMI one of the highest recorded population growth in the world, measured at 5.6% per year over the past decade. The 1999 population has increased about 82% since 1980 due to non-resident workers and migration from other islands. There has also been a high rise in birth rates due to immigrants wanting children born in a U.S. territory (*CNMI Title II application*).
- ξ In FSM, there is a strong trend of migration from the outer islands to the state centers which contain 81% of the total population. Additionally, upwards of 15,000 FSM are currently living in Hawai'i and the U.S. mainland, Guam, and CNMI pursuing educational and employment. However, the rate of permanent emigration to the U.S. from FSM is low, as many FSM citizens return (*FSM Title II application*).
- ξ Guam's population is the largest, at 154,623 with a growth rate of 1.9%. Northern Guam is the fastest growing region of the island, the population there having increased by 32% between 1980 and 1990. Of the total population, about 30,000 are military personnel and their dependents (*OIA Report, 1999*).
- ξ Palau residents are also highly mobile and travel off island frequently where there is continuous exchange between resident and overseas Palauain communities. A 1990 Palau Health Survey found that 30% of the population had traveled off-island in the preceding year and that 44% of the male travelers, and 15% of the female travelers engaged in sexual relations while off island (*Palau Title II application*).

Migration is a key issue in examining factors that impact health care access and delivery. For many jurisdictions, immigration has caused some strain on infrastructure development and health services in prevention and care for STDs and HIV/AIDS, pre- and post-natal care, tuberculosis and Hepatitis B. A regional approach to health care delivery can also begin to address the gaps that occur when a mobile and rapidly rising population attempts to access health information and care.

#### CULTURE, LANGUAGE AND SOCIETAL STRUCTURES

Each of jurisdictions also has a distinct cultural history plus a wide array of languages and dialects. Internally, there are also distinctions among different islands, states and regions while sharing common economic and some cultural and linguistic bonds.

Each jurisdiction has a very diverse population and unique population distribution. For example, Guam has no single ethnic group constituting more than 50% of the population although Chamorros make up the largest ethnic group (47%). In American Samoa, Samoans make up the majority (89%); Tongans, Western Samoans, Fijians and others make up a small percentage of the population. Guam, CNMI also have growing Asian immigrant populations. Filipinos, Japanese and other Asians make up 37% of the population in Guam and 52% in CNMI (*OIA Report, 2000; CIA Factbook, 2000*).

While English is the language used mostly in government and commerce in all the Pacific Island jurisdictions, English is not the language commonly spoken at home and in the communities. All jurisdictions have 2 or more official indigenous languages in addition to English, as well as other languages and dialects that are often spoken in the outlying islands and atolls, and among immigrant



populations. For example, FSM has at least 9 different major indigenous languages as well as many dialects. Palau has 4 other official languages for their outlying states.

Delivery of healthcare is also tied to cultural norms, values and structures. Barriers arise when community members have difficulty openly discussing sexually related matter especially between members of the opposite sex. Because of the small population and the cultural emphasis on extended family structure and kinship, most people in the islands are either related or know of each other, including the health care providers. This causes additional discomfort as well as additional challenges in receiving confidential HIV and other medical care. Cultural and communication barriers also arise when new populations migrate. For example, the sharp rise in population in CNMI and Palau due to the influx workers from Asia has caused many strains on the island's infrastructure, utilities and education programs (*OIA Report, 1999*). Many immigrants who often carry the same stigma and discomfort about discussing issues of sex, family planning, STDs and HIV are also have difficulty accessing information in their language. These cultural and linguistic constraints create difficulties for health workers, parents, teachers and community leaders to inform and educate community members about HIV and STDs. Gender also plays a strong role in who and how someone gets health information and healthcare. For example in RMI, men are seen as guardian, provider and decision maker; therefore men are traditionally trained as health assistants by the Department of Public Health. Especially in the outer atolls, the vast majority of health assistants are men, making it challenging for women to access health care (*RMI Title II application*).

#### ECONOMY: RESOURCES, DEVELOPING INDUSTRIES AND THE IMPACT ON HEALTH

The economies of the Pacific Island Jurisdictions are mixture of subsistence and monetized economies. Due to the jurisdictions' small size, relative isolation from major centers of trade, limited number of natural resources, a population highly dispersed among numerous, distanced atolls and islands, and political and economic history with the U.S., the Pacific Island Jurisdictions are extremely constrained in its economic growth and development. The economies mainly remain dependent on the government sector, but there are growing private industries in fishing, tourism, construction, and garment manufacturing. The U.S. military also has a strong economic impact in both the public and private sectors in Guam, CNMI and RMI. Tourism, military presence, as well as the influx of immigrant workers for other industries is showing strong impact on the commercial sex industries in Palau, CNMI and Guam. Also there is increased drug consumption and demand from tourists in CNMI (*Palau Title II application; CNMI Title II application; OIA Report, 1999*).

#### YOUNG POPULATION

The region as a whole has a high number of sexually active people between the ages of 15-39. In 1995, for example, Palau estimated 44% of its population was in the 15-39 age groups, RMI estimated 42%, and Guam estimated 28.31%, compared with U.S. average of 27.78%. This young population also shows high HIV co-factors such as gonorrhea and syphilis (*see needs assessment section*). In addition the percentage of individuals below the age 15 is also high: RMI estimated 48.9%, Guam estimated 34.5%, and FSM estimated 43% compared with the U.S. average of 21.41%. As this group ages, HIV and STD rates are predicted to steadily increase. In addition to high STD rates, adolescents show high risk sexual behaviors. Among CNMI teenagers surveyed in 1997, 21% stated they had sexual intercourse before the age of 13, which was increase from 15% in 1995. In the 1997 Youth Risk Behavior Survey, 31% of high school students admitted to having 4 or more sexual partners. Although condom use is increasing among junior high school students, the rate decreased among high school students from 33% in 1995 and only 24% in 1997 (*CNMI prevention application*). In a 1999 Youth Risk Survey in Palau, adolescents indicated being in sexual relationships (71% and 26% of girls). Boys were more likely than girls to be sexually active at a young age: 21% of boys and 2% of girls indicated sexually activity before the age of 13. Approximately one third of sexually active youth reported using drugs or alcohol during their last sexual encounter (*Palau Title II application*).

The Pacific Island jurisdictions are diverse in culture, language, economy, population distribution and history, but they share commonalities in rapidly growing populations, rising rates in STD and HIV co-factors, barriers caused by geographic isolation and a dispersed population, poverty, diversifying ethnic communities, and the need for comprehensive health care services, including HIV/AIDS services. Also common is the shift in economies from subsistence living to wage earning and urban drift, which causes changes in lifestyle and disruptions in societal values, family ties and cultural norms

### Current HIV Service Delivery System

There is no comprehensive continuum of HIV care services in any of the jurisdictions. Furthermore, there is a lack of coordinated HIV care services in the region.

### HIV SERVICES IN THE PACIFIC ISLAND JURISDICTIONS

Health care delivery in the region comes under the Department or Ministry of Health and is divided between the hospital services and the public health departments. There are few non-governmental agencies (in all areas of health and social services, including HIV/AIDS) in the Pacific jurisdictions. All the jurisdictions rely on the strengths of their health departments, hospitals, and Ministries of Health for the majority of their health care and social service needs.

HIV Services, including prevention and care, are provided mainly through the public health departments. While there are some private providers that see PLWHA in Guam and CNMI, most of the jurisdictions do not have this luxury. In all of the jurisdictions, the health departments play a key role in the provision on HIV services. However, in most jurisdictions, these programs have only a handful of staff, with HIV programs usually combined with STD programs. The only AIDS service organization in the region, Coral Life Foundation, has only two staff. Founded in 1993, Coral Life Foundation was the first non-governmental organization based in the Pacific Island region to receive federal funds for HIV prevention in 1999.

At the last PIJAAG meeting in April, 2001, participants from the jurisdictions helped compile a matrix of HIV services currently available in the region. Additional information was gathered from HIV prevention applications.

### MATRIX OF SERVICE RESOURCE INVENTORY

JURISDICTION	Outreach	Pre-test Counseling	Testing	Post-test Counseling	Partner Notification	Individual Level Interventions	Group Level Interventions	Community Level Interventions	Media	Referrals	Primary Care	Outreach to PLWA	Early Intervention Services	Medication Availability	Case Management	CD4 Count	AETC
CNMI	X	X	X	X	X	X	X	X	X					*4			
FSM-Pohnpei	X						X	X	X					*4			X
FSM-Chuuk	X		X*3		X	X	X	X	X	X				*4			
FSM-Yap	X						X	X	X					*4			
FSM-Kosrae	X													*4			X
Guam	X	X	X	X	X	X	X	X	X	X	X			X		X	
Palau	X	X	X	X	X	X*2	X	X	X					*4			
RMI	X	X	X	X	X	X	X	X	X	X				*4			
American Samoa	X	X	X	X	X	X*1	X	X	X			X		*4			X

Prevention -----! Care

\*1 Needle Sticks

\*2 No Curriculum

\*3 Clinic

\*4 Not Routinely Available



An initial reading may indicate that a fair amount of HIV services (specifically prevention) is currently being provided. However, a more detailed investigation is needed to understand the full scope of the situation in the region. While all jurisdictions are providing HIV prevention interventions to their local populations, there is much variation in the thoroughness of those interventions. For example, FSM is providing HIV antibody testing (in Chuuk), but doesn't have the current capacity to provide pre- and post- test counseling, a critical component of all HIV prevention strategies. Also, testing in FSM is not available in every state and is inaccessible because of transportation, time, and cost to travel inter-island. Testing itself has been an issue, as lab work needs to be sent off island to Hawai'i or Australia; FSM and Palau currently are having problems with the only air carrier for the region, Continental Micronesia, which refuses to transport "infectious agents", even if the specimens are properly packaged. Other problems include the time it takes for the test results to be returned; in American Samoa, there are only two flights a week (Mondays and Fridays) and tests may take 4-6 weeks to be returned. In at least one instance, results took 2 months (*PIJAAG April meeting*). Currently, only Guam and FSM (Chuuk) has lab facilities on-island to conduct Elisa tests. However, all Western Blot confirmatory tests must be sent to Hawai'i or Australia. Safe blood supply is also an issue for some of the jurisdictions, with both FSM and American Samoa currently not screening donated blood (*PAETC 2000 Report and PIJAAG February meeting*). This is due to the lack of equipment and staff training to test the supply.

HIV care services fairs much worse, with only Guam currently offering HIV-specific primary care services to PLWHA. Guam is able to provide CD4 counts and viral load testing; other jurisdictions cannot. Guam also has funds for drug therapies; the other jurisdictions do not. However, Guam is limited in its resources and cannot offer early intervention or case management services. With this gap, Guam is NOT able to provide client-centered services to link individuals with primary health care, psycho-social and other services in a timely manner; provide on-going assessment of the client's needs, and development of a service plan. Guam's health department does work closely with the only AIDS service organization in the region, Coral Life Foundation, to provide some limited HIV care services (through foundation money) and HIV prevention, but the resources are minimal.

CNMI has some of the infrastructure to provide primary health services to PLWHA, though not specifically HIV primary care. There is some coordination plans with other federal services as well as linkages with prevention and substance use programs. Recently, the HIV/STD Program has been given a government building that in the future will be a center for PLWHA support activities.

The Republic of Palau is in the early stages of development, with no specific HIV care services currently in place. With 2 new cases in 2000 and 2001, Palau is facing difficult situations because of the lack of HIV care service infrastructure. Medications have been initiated to prevent prenatal transmission for an HIV positive pregnant woman; however, the treatment was initiated without baseline CD4 counts and viral load testing, currently unavailable in Palau. Blood specimens, as previously mentioned, aren't accepted by the only airline carrier in the region. Medication for this woman had to be borrowed from another jurisdiction. Provision for future treatment of PLWHA in Palau is still not clear (*Palau Title II application*). American Samoa, RMI and FSM currently do not have HIV care services and are in the process of its development. Both RMI and FSM do not have funds for medication (and are ineligible for Medicaid programs). Currently in FSM, the only treatments available to PLWHA are antibiotics and intravenous fluids (*PIJAAG April meeting, FSM Title II application*).

It is recognized that all jurisdictions provide primary care to people in need of services, including PLWHA, through their public health care systems. However, with the complexity and specialization needed to adequately provide HIV care to PLWHA, these systems alone are hardly adequate. Only Guam currently has the capacity to provide some HIV-specific primary care services. The need for capacity-building in the jurisdictions is real and apparent. This regional model is an opportunity for the jurisdictions to develop not only their own infrastructure, but the region's as well.

## BARRIERS THAT IMPACT ACCESS TO CARE

The main barriers for PLWHA in the Pacific Island Jurisdictions are the lack of a continuum of HIV care services in each jurisdiction and the lack of coordinated care services in the region. PLWHA may not be accessing services because, in most jurisdictions, there are no services to access.

- ξ The lack of HIV care services in each jurisdiction.
- ξ The lack of coordinated HIV care services throughout the region has repeatedly been reported as a barrier to care with migration throughout the region. For example, PLWHA must have their HIV positive status confirmed through another HIV test before accessing services in another jurisdiction. This, as described earlier, can be an extremely long process (*PIJAAG April meeting*).
- ξ The lack of case management services means PLWHA need to be able to self-advocate and maneuver through a health care system. As these systems are not HIV-specific care services presents other barriers (*see next bullet below*)
- ξ Confidentiality issues and fear of being ostracized still are common concern of PLWHA in the region. Many seek services elsewhere, only seek services at end stages of the disease, or don't seek services at all.
- ξ Currently available continuum of HIV care services (Honolulu, Hawai'i) are inaccessible due to the distance and the cost.
- ξ Currently, no jurisdiction is providing outreach for HIV care services (presumably because the services are not available)
- ξ There still exists a denial in the jurisdictions that HIV/AIDS is in the community and a denial of the possibility that one is at risk (*PIJAAG February meeting*). People therefore do not access care services because they do not think it is possible for them to be HIV positive.

## FEDERAL, STATE, AND PRIVATE FUNDING FOR HIV PREVENTION AND CARE SERVICES

All jurisdictions will be receiving Title II funds this year at the baseline amount (\$50,000) for HIV care services. Additionally, Guam receives some ADAP funds. Each jurisdiction also receives CDC funds for HIV prevention activities; 5 of the 6 also receive Division of Adolescent School Health (DASH) funds. DASH funds the Youth Risk Behavior Survey which measures priority health-risk behaviors among youth, including HIV/STDs.

Coral Life Foundation, in Hagatna, Guam, also receives funding through the Guam Department of Public Health, through CDC, and through private foundations like the Gill Foundation and Mac Cosmetics.

Title II funds will help build some capacity in each jurisdiction, but does not address the regional approach needed to work effectively in the Pacific. Each jurisdiction will continue to develop its HIV care services through their newly awarded Title II funds. However, these jurisdictions are newly funded and will need on-going assistance to ensure each jurisdiction is able to provide a continuum of HIV care services appropriate to their area. At their base funding of \$50,000 per year, this is hardly enough to support a continuum of HIV care services. Without sharing of resources through a regional model, jurisdictions will not be able to achieve baseline HIV care services. Sharing resources in the region will be critical in ensuring all PLWHA will have access to HIV primary care services, early intervention, and case management.

### Gaps / discuss why this plan fills those gaps

The main gaps in HIV primary care in the Pacific Island Jurisdictions are the lack of coordinated care services in the region and the lack of a continuum of HIV care in each jurisdiction.

The Guam Conference Report from the University of Hawai'i on its recent HIV/AIDS conference (January 2001) for physicians, nurses, and other health care professionals in the Pacific Island region identified five areas of need for the management of HIV in the jurisdictions. 1) Communication among the jurisdictions needs to be improved, including the sharing of information about migrating PLWHA throughout the region. The group suggested a tracking mechanism, but realized the complexity of coordination and protection of client confidentiality. Communication between the



regions also would help peer-to-peer support. 2) Communication and support within each jurisdiction is needed to coordinate HIV care services. 3) The jurisdiction needs to have access to information from outside the region. 4) Training for health care providers and the community-at-large on the continuum of HIV related issues and community mobilization strategies are needed. 5) Funding for programs, training, and medications is needed (*University of Hawai'i Guam Conference Report*).

The findings from this report are similar to APIAHF's assessment and its objectives stated to address them. This project provides a unique regional approach that can more effectively and efficiently address the lack of HIV care services in the jurisdictions. This project will build the HIV care service delivery capacity of the region, through overall regional activities coordination, regional capacity-building assistance, as well as one-on-one capacity-building with each of the jurisdictions. The projects will 1) increase coordination and collaboration between the jurisdictions, 2) develop and support HIV training and technical assistance in the region, and 3) work with each jurisdiction to develop capacity for baseline standard of HIV care services. Objectives include yearly training to increase capacity to serve HIV clients, standardized policies and procedures for the region to ensure client confidentiality and rights, enhancement of each jurisdictions' internal infrastructure to provide services, and the development of a shared medical records system between the jurisdictions.

This proposal is coordinated with the Title III Planning Grants each of the six jurisdictions is submitting. Those planning grants will develop local linkages to care services and continue development of their local HIV needs assessment. APIAHF will be working with each jurisdiction to conduct a regional needs assessment and develop a comprehensive model of care in coordination with their planning grant activities.

## **Organizational Capacities and Expertise**

### **CURRENT ORGANIZATIONAL CAPACITIES AND EXPERTISE OF APIAHF**

APIAHF is a national minority organization seeking to improve the health status of Asians & Pacific Islanders through data development and research, policy development and advocacy, information collection and dissemination, and capacity-building assistance. This proposal continues APIAHF's activities to support HIV program capacity-building in the region.

Since the beginning of the HIV epidemic, APIAHF has provided national leadership on HIV/AIDS issues in the Asian & Pacific Islander communities. APIAHF has included HIV/AIDS in its national health agenda since its 1988 national conference, "Breaking the Barriers: A National Agenda for Asian & Pacific Islander Health". APIAHF was the original fiscal agent for both the Filipino Task Force on AIDS (1988) and the Gay Asian Pacific Alliance Community HIV Project (GCHP)(1989), two of the earliest Asian & Pacific Islander AIDS service organizations, until they were able to obtain their independent non-profit, tax-exempt status. GCHP later merged with another agency, Asian AIDS Project, to become the Asian & Pacific Islander Wellness Center, the largest Asian & Pacific Islander AIDS service organization in the U.S. APIAHF also was instrumental in advocating for and developing the Department of Health and Human Services Initiative on Asian Americans and Pacific Islanders, begun in 1997. APIAHF staff assisted in the planning and implementation of HRSA invitational meeting on Asian Americans and Pacific Islanders in March 1998. Among the recommendations from that invitational meeting were increased resources for capacity-building for Pacific Island Jurisdictions. More recently, APIAHF was a subcontractor on a HRSA project assessing the HIV-related care and treatment needs of gay and bisexual Asian American and Pacific Islander men living with HIV/AIDS. APIAHF also has been providing comments on an HIV/AIDS Bureau analysis of Ryan White CARE Act client-level data about Asian Americans and Pacific Islanders from California. A final manuscript from the HIV/AIDS Bureau has now been submitted for publication.

For the past eight years, APIAHF has provided organizational and programmatic Capacity-Building Assistance to community-based organizations and health departments working with Asian & Pacific Islander populations in their HIV prevention interventions. Funded through the CDC and the Office of Minority Health as a capacity-building assistance provider, APIAHF has utilized a peer-to-peer model that supports national and regional alliances and collaboration. APIAHF itself works with five partner agencies to provide capacity-building assistance: Asian & Pacific Islander Wellness Center (San Francisco, California), Asian Pacific AIDS Intervention Team (Los Angeles, California), Asian & Pacific Islander Coalition on HIV/AIDS (New York, New York), Asian Health Coalition of Illinois (Chicago, Illinois), and Malama Pono (Lihue, Hawai'i). Four of APIAHF's partner agencies receive Title I, II, and/or Title III funds; all will be available to help provide capacity-building assistance to the jurisdictions. Given the location of Asian & Pacific Islander Wellness Center in California and Malama Pono in Hawai'i, however, these organizations will provide main support for this project. APIAHF has a long history of involvement with regional networks, such as the East Coast Asian & Pacific Islander AIDS Network, the Hawai'i Multi-cultural HIV Resource Project, and the Los Angeles Asian & Pacific Islander AIDS Caucus. APIAHF's work with PIJAAG continues its commitment to this process. APIAHF has also been supporting the development of several working groups, including the Asian & Pacific Islander Women's HIV/AIDS National Network and the National Asian & Pacific Islander Youth HIV Working Group, both which have had significant jurisdictions involvement.

Capacity-building assistance is provided in five major areas: Organizational Development, Program Development, Community Capacity-Building, HIV Prevention Community Planning, and New Technology. Capacity-building assistance is provided through our partner agencies, through national meetings and conferences, information sharing, minigrants, and on-going, sustained one-on-one technical assistance sessions.

A partial list of the projects and activities APIAHF has helped convene in the past three years: *PIJAAG Meetings (February, March, April 2001)* \* *Hawai'i Community Planning Leadership Orientation Training (February 2001)* \* *Asian & Pacific Islander Institutes at Community Planning Leadership Summit and U.S. Conference on AIDS (1999, 2000, 2001)* \* *Asian & Pacific Islander MSM Evaluation meeting (June 2000)* \* *National Asian & Pacific Islander Community Planning Group Meeting* \* *Asian & Pacific Islander Leadership Meeting (February 2000)* \* *National Asian & Pacific Islander HIV/AIDS Summit (September 1998)* \* *HIV Prevention in the Pacific: A Technical Assistance & Training Workshop (August 1998)* \* *A Review of HIV Prevention Materials in Asian & Pacific Islander Languages* \* *Technology Minigrants* \* *National Asian & Pacific Islander Youth Working Group* \* *Asian & Pacific Islander Women's HIV/AIDS National Network*

APIAHF's HIV CBA Program staff have over ten year combined in HIV/AIDS programming and over ten year combined of HIV capacity-building assistance provision. Prescott Chow, the program manager who will be responsible for the project oversight, has worked with APIAHF's HIV Capacity-Building Assistance Program for over three years. He has experience administering federal grants for the program and has managed its yearly \$700,000 budget, of which \$261,000 goes back into the communities through subcontracts with partner agencies and technology minigrants. Mr. Chow has consulted with HRSA as a Title III planning grant reviewer, participated as a steering committee member of the CDC-sponsored 2001 Community Planning Leadership Summit, participated as a reviewer for CDC program announcement 023, and provided on-going consulting on the CDC Community-Based Organization Evaluation Guidance. APIAHF HIV Capacity-Building Assistance Program staff have experience with HIV service programming as well. Prescott Chow formerly worked at Asian & Pacific Islander Wellness Center as its Associate Director of Community Programs and ManChui Leung, program coordinator, formerly worked at Chinese American Planning Council as its Associate Program Director.

APIAHF has worked with the Pacific Island Jurisdictions throughout its ten-year organizational history. In 1998, APIAHF collaborated with capacity-building assistance providers Asian & Pacific Islander Wellness Center, National Minority AIDS Council, as well as CDC and the Guam



Department of Public Health and Social Services to develop and evaluate HIV prevention programs, improve HIV prevention community planning group efforts, and discuss issues affecting the region (migration of populations, etc). The follow-up activities from that meeting included a Counseling Testing Referral and Partner Notification training in Atlanta (1999) and the *Hawai'i Community Planning Leadership Orientation Training* (2001). Since then, APIAHF has continued its involvement in the jurisdictions, especially with the Coral Life Foundation, the only AIDS service organization in the region, on organizational as well as programmatic capacity-building issues.

In the past four months, APIAHF has supported the development of PIJAAG through the convening of meetings, facilitating conference calls, and providing logistical, administrative, and practical assistance. PIJAAG is dedicated to the strengthening and enhancement of an HIV continuum of prevention and care services in the Pacific Island jurisdictions. All PIJAAG participants are local to the islands; all participants are Pacific Islander or Asian. As an advisory committee for this grant, PIJAAG will provide an integral role in the implementation and development of this project. With the core membership of PIJAAG consisting of the AIDS directors and program managers responsible for both prevention and care services from each of the jurisdictions, PIJAAG provides a unique opportunity for an integrated approach to HIV in the Pacific, on both a local and regional level. Coral Life Foundation, as the only AIDS service organization in the jurisdictions, also provides critical indigenous leadership for the Pacific Island region. As a subcontractor on this project, Coral Life Foundation will work with each jurisdiction to develop a regional model for a continuum of HIV care services.

This Title III Capacity-Building Grant will strengthen the existing partnership APIAHF shares with the Pacific Island Jurisdictions. Although APIAHF is not a direct service provider, this grant will be used to build capacity for HIV care services in the Pacific Island region in keeping with the goals and objectives of Title III. APIAHF's experience with capacity-building assistance and its relationship with the Department of Health and Human Services would benefit not only the region, but the relationship between the federal agencies and the jurisdictions as well.

APIAHF's overall agency budget for fiscal year (July 1, 2000 – June 30, 2001) is as follows:

Revenue		Expenses	
Grants	2,861,937	Salaries & Wages	1,240,018
Subcontracts Income	638,666	Benefits / Payroll Taxes	285,204
Donations	70,000	General Operating	709,797
Fees	36,000	Consultants / Professional Services	201,935
Miscellaneous Income	-	Subcontracts / Minigrants	854,774
<b>TOTAL REVENUE</b>	<b>3,606,603</b>	Facilities	60,628
		Conference Expenses	200,000
		<b>TOTAL EXPENSES</b>	<b>3,552,356</b>
		<b>Net Surplus (Deficit)</b>	<b>54,247</b>
		Equipment & Furniture	53,285
		<b>TOTAL NET REVENUE (EXPENSE)</b>	<b>962</b>

APIAHF is structured into four Divisions: Community Health Development, Policy, Data and Research, and Executive Office. APIAHF's HIV Capacity-Building Assistance Program is contained in the Community Health Development Division, together with the Asian & Pacific Islander Tobacco Education Network, Asian & Pacific Islander Institute on Domestic Violence, and the Asian & Pacific Islander National Cancer Survivor Network. APIAHF's Policy Division projects include the Asian American & Pacific Islander Health Improvement Project, Health Interpretation and Linguistic Access Project, and Coalition for the Elimination of Racial and Ethnic Health Disparities. APIAHF's Data and Research Division projects include the Asian & Pacific Islander Center for Census Information and Services, Asian Indian Cardiovascular Project, and the National Research Advisory Consortium.

APIAHF has strong fiscal and human resources staff and systems that will ensure compliance with all the terms and conditions of the program announcement. Both our Finance Coordinator and Finance Director have over ten years of experience each in the administration of non-profit organizations. APIAHF follows clear written fiscal, administrative, and operations policies and procedures. Written staff evaluations are conducted on an annual basis and each staff person has an individualized staff development and training workplan.

The HIV Program manager, Prescott Chow, is supervised by the Policy Director, Ignatius Bau. Mr. Bau is the former manager for the HIV Program and is currently on the Presidential Advisory Council on HIV/AIDS. Prescott Chow also supervises two staff: ManChui Leung, program coordinator, and Rachel Gacula, program associate. Both Ms. Leung and Ms. Gacula have been involved with PIJAAG activities; their time will be provided in-kind for this project.

### **Role in the Community / Collaboration with other organizations**

APIAHF will be collaborating with several different organizations and entities for this Title III project. Most of these collaborations build on existing relationships with the jurisdictions, with PIJAAG, with Coral Life Foundation, and with CBA providers. APIAHF will also be exploring a new collaborative relationship with the Pacific AIDS Education & Training Center.

PIJAAG: PIJAAG has the most prominent collaborative role as the advisory committee of this Title III project.

- § PIJAAG will be instrumental in the regional and local coordination and implementation of assessments and trainings on HIV service issues.
- § PIJAAG will also be involved in the development of policies and procedures for HIV care services in the region.
- § Additionally, PIJAAG will pilot the medical records system to share information throughout the region.
- § Finally, PIJAAG will advise APIAHF throughout the contract period on the project to ensure the goals and objectives continue to meet the needs of the jurisdictions.
- § APIAHF will hold quarterly conference calls, in-person meetings (provided in-kind through its CDC cooperative agreement), and provide support for the continued development of this group.

Given the unique situation in the Pacific Island region, each jurisdiction will have a significant role in this project, collaborating under both their Title II and Title III grants.

CORAL LIFE FOUNDATION: Coral Life Foundation will be a subcontractor on this project to provide regional coordination.

- § Coral Life Foundation will develop communications systems between the jurisdictions to enhance collaboration and support
- § Coral Life Foundation will help develop policies and procedures on client confidentiality, client and provider rights, etc.
- § Coral Life Foundation will help develop a training on Public Health Service Standards of Care to strengthen each jurisdictions' capacity to provide baseline HIV services
- § Coral Life Foundation will work with each jurisdiction to analyze needs and develop a regional assessment of HIV care services.
- § Coral Life Foundation will help convene case conferencing calls with the jurisdictions to enhance HIV services.
- § Coral Life Foundation will help develop and execute yearly conference on HIV service issues.
- § Coral Life Foundation will work with capacity-building assistance providers to support on-going technical assistance for the jurisdictions.

### **TITLE II GRANTEES AND TITLE III PLANNING GRANTEES**

- § Title II funds may be made available to help support the yearly HIV care services trainings.



- ξ Title II grantee will share resources as necessary to ensure the conservation and best use of resources (e.g. collaborate on assessments, sharing of epidemiological profiles, etc).
- ξ APIAHF will be sharing the information, materials, and trainings with Title II grantees.
- ξ Each jurisdiction's local Title III coordinator will share its needs assessment with the Regional coordinator.
- ξ Each jurisdiction's local Title III coordinator will work with the Regional coordinator to develop the regional needs assessment.

CAPACITY-BUILDING ASSISTANCE PROVIDERS: Asian & Pacific Islander Wellness Center and Malama Pono, both current capacity-building assistance providers subcontracted under APIAHF's CDC cooperative agreement, will be collaborating agencies with this project. In addition, Malama Pono will work with the Hawai'i Multi-cultural HIV Resource Project, a coalition comprised of the five AIDS service organizations in the Hawaiian Islands, to access additional capacity-building assistance resources. Malama Pono will also help facilitate the involvement of the Hawai'i Department of Public Health in this collaborative project.

- ξ Capacity-Building Assistance Providers will help provide on-going CBA to the jurisdictions on HIV care service delivery.
- ξ Capacity-Building Assistance Providers will help develop yearly trainings on HIV care issues.

PACIFIC AIDS EDUCATION & TRAINING CENTER: APIAHF and Pacific AIDS Education & Training Center, one of the regional training center funded by HRSA's HIV/AIDS Bureau to provide education and training for primary care professionals, will continue to explore collaborative activities with this project.

- ξ Pacific AIDS Education & Training Center and APIAHF will share assessments to enhance both organizations' ability to work effectively with the jurisdictions.
- ξ Pacific AIDS Education & Training Center and APIAHF will explore collaboration on the yearly trainings (e.g. sharing faculty)
- ξ Pacific AIDS Education & Training Center and APIAHF will share training schedules to ensure best use of resources.

### **Involvement of People Living with HIV/AIDS**

As the only AIDS service organization in the region, Coral Life Foundation's role in this project is invaluable. The organization has been a representative for this community, not only in Guam but throughout the region. Coral Life Foundation will continue to play this role as a member of PIJAAG, the advisory committee to this project. Coral Life Foundation will be a subcontractor on this project to provide regional coordination and be involved in other project activities. Coral Life Foundation's executive director, Mr. Vince Crisostomo, is also well known in the HIV community in the Pacific as well as in the continental U.S. As an out PLWHA, Mr. Crisostomo has been a vocal national advocate for PLWHA. As one of only a handful of openly HIV positive Pacific Islanders in the jurisdictions, he has continued his commitment to PLWHA issues. He is also the chair of PIJAAG.

Past PIJAAG meeting participants included AIDS directors, program staff, as well as community stakeholders (HIV prevention community planning members, youth, PLWHA, etc). The group will continue to invite and include other community members as appropriate.

With this project, the Regional Coordinator (designated through Coral Life Foundation) will be working with each jurisdiction to complete needs assessments for the jurisdictions and for the region. Part of this assessment will include interviews and/or surveys of at least five PLWHA or HIV service providers in each jurisdiction. The Regional Coordinator will conduct additional key informant interviews with at least six PLWHA in the region to make sure PLWHA representation is included in this capacity-building project.

## Proposed Capacity-Building Activities / Workplan

**Problem Statement:** *There is no system of care for Pacific Islanders with HIV/AIDS in the six U.S. Pacific Island Jurisdictions.*

Goal I: Develop coordination and collaboration between the jurisdictions around HIV services.			
Objective	Key Action Steps	Evaluation Methods	Person Responsible
Objective 1: By October 31, 2001, APIAHF will support a coordinated regional continuum of HIV services by designating a regional coordinator to work with each individual jurisdiction coordinator.	1.1 hire consultant to serve as regional coordinator by October 31, 2001	1.1 Completion of the hiring process for the regional coordinator.	1.1 Prescott Chow, Program Manager
	1.2 develop communications system between coordinator and local jurisdiction coordinators by December 31, 2001	1.2 Regional coordinator establishing contact with PIJAAG and PIHOA	1.2 Regional Coordinator, to be hired
	1.3 develop policies and procedures with the jurisdictions (e.g. confidentiality, client and provider rights, grievance procedures, intake, data collection, fiscal issues, etc) by February 28, 2002	1.3 Complete Policy and Procedures Manual by February 28, 2002.	1.3 Regional Coordinator, to be hired, with PIJAAG
	1.4 develop regional training on Public Health Service Standards of Care by August 30, 2002	1.4 Develop curriculum for Public Health Standards of Care by June 30, 2002	1.4 Regional Coordinator, to be hired, with PIJAAG
	1.5 create a plan to maximize services in the region by August 30, 2002	1.5 Develop and begin implementation of a regional work plan February 01 2002.	1.5 Regional Coordinator, to be hired, with PIJAAG
	1.6 develop training components for Goal II, Objective 5 for Year 01	1.6 Begin to conduct needs assessment and identify jurisdiction specific and region wide priorities March 31, 2002.	1.6 Regional Coordinator, to be hired, with PIJAAG
	1.7 monitor progress throughout 2 years		1.7 Prescott Chow, Program Manager



Objective 2: By August 30, 2002, APIAHF will help develop and strengthen coordination of the region's HIV primary care services by compiling and analyzing needs assessments from each of the jurisdictions to inform and guide assessment of the region.	<p>2.1 work with each jurisdiction to compile needs assessments by February 28, 2002</p> <p>2.2 analyze assessments by May 30, 2002</p> <p>2.3 summarize, draw on assessments to create regional assessment by August 30, 2002</p> <p>2.4 use additional focus groups and/or key information interviews to complete regional view by August 30, 2002</p>	<p>2.1 - 2.2 Complete assessment and analyses of jurisdiction specific needs to identify priorities for follow up by February 28, 2002.</p> <p>2.3 - 2.4 Complete assessment and analyses of jurisdiction wide needs to identify at least two priorities for follow up by August 30, 2002.</p> <p>2.4 Develop a long-term plan for regional collaboration by August 30, 2002</p>	<p>2.1 Regional Coordinator, to be hired</p> <p>2.2 Regional Coordinator, to be hired</p> <p>2.3 Regional Coordinator, to be hired</p> <p>2.4 Regional Coordinator, to be hired</p>
Objective 3: By August 30, 2003, APIAHF will help develop and strengthen the region's HIV primary care capacity through a coordinated medical records system to share client information between the jurisdictions.	<p>3.1 work with each jurisdiction to assess need and capacity re medical records systems by August 30, 2002</p> <p>3.2 investigate software, hardware and other resources needed to implement shared medical records system by August 30, 2002</p> <p>3.3 prioritize equipment necessary by December 31, 2002</p> <p>3.4 pilot test system by March, 2003</p> <p>3.5 train during yearly Goal II Objective 6 training by August 30, 2003</p>	<p>3.1 Completion of data flow chart models for medical records based on needs assessment by Oct 30, 02.</p> <p>3.2-3.3 Complete initial personnel training and put in place technology for data collection and management by March 31, 2003.</p> <p>3.4 Draft policies for use and access to the data by December 31, 02.</p> <p>3.5 Evaluate process and outcome of annual trainings.</p>	<p>3.1 Prescott Chow, Program Manager</p> <p>3.2 Prescott Chow, Program Manager</p> <p>3.3 Prescott Chow, Program Manager</p> <p>3.4 PIJAAG</p> <p>3.5 PIJAAG</p>

*Problem statement: There are few culturally competent training and technical assistance opportunities accessible to HIV service providers in the Pacific Island Jurisdictions.*

Goal II: Develop and support HIV training and technical assistance in the region.			
Objective	Key Action Steps	Evaluation Methods	Person Responsible
Objective 4: By August 30, 2003, APIAHF will support HIV service enhancement through three case conferences on client service issues in the region	<p>4.1 compile list of appropriate service providers in each jurisdiction by September 30, 2001</p> <p>4.2 send out invitations to first case conferencing call, follow up with calls by December 31, 2001</p> <p>4.3 participants complete Goal I Objective 1 confidentiality procedures by February 28, 2002</p> <p>4.4 convene first case conferencing call by March 30, 2002</p> <p>4.5 conduct follow up with one-on-one technical assistance as appropriate</p> <p>4.6 convene at least two additional conference calls by August 30, 2003</p>	<p>4.1 Create a list of appropriate HIV service providers for the region by September 30, 2001.</p> <p>4.2-4.6 Completion of the three case conferences along with process evaluation by August 30, 2003.</p>	<p>4.1 Regional Coordinator, to be hired, with PIJAAG</p> <p>4.2 Regional Coordinator, PIJAAG</p> <p>4.3 Regional Coordinator</p> <p>4.4 Regional Coordinator, PIJAAG</p> <p>4.5 Regional Coordinator, APIAHF and other CBA Providers</p> <p>4.6 Regional Coordinator, PIJAAG</p>

Objective 5: By August 30, 2003, APIAHF will support HIV service enhancement by convening a yearly training to address client service issues in the region	<p>5.1 utilizing needs assessment from the jurisdictions as well as Goal I Objective I coordinated activities, create draft training agenda for Year 01 training by March 30, 2002</p> <p>5.2 develop training through committee by May 30, 2002</p> <p>5.3 investigate and secure logistics by May 30, 2002</p> <p>5.4 invite sponsored attendees by May 30, 2002</p> <p>5.5 convene Year 01 training by August 30, 2002</p> <p>5.6 convene Year 02 training, with Goal I Objective 3 medical records systems training component by August 30, 2003</p>	<p>5.1-5.2 Complete curriculum on topics prioritized through the needs assessment from Objective 2.2 by March 31, 2002.</p> <p>5.3- 5.5 Conduct and evaluate process and outcome of all trainings through September 2003.</p> <p>5.3-5.5 Evaluate need for further trainings during all trainings done through September 2003.</p> <p>5.6 Complete Year 02 training medical records system curriculum May 30, 2003.</p>	<p>5.1 Prescott Chow, Program Manager</p> <p>5.2 Prescott Chow, Program Manager, PIJAAG, APIAHF and other CBA providers</p> <p>5.3 Regional Coordinator, to be announced</p> <p>5.4 PIJAAG</p> <p>5.5 Prescott Chow, Program Manager, PIJAAG, APIAHF and other CBA providers</p> <p>5.6 Prescott Chow, Program Manager, PIJAAG, APIAHF and other CBA providers</p>
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*Problem statement: There are specific internal capacity issues in each of the jurisdictions that prohibits the provision of baseline standard of HIV CARE services.*

Goal III: Work with each jurisdiction to develop capacity for delivery of baseline standard of HIV CARE services.			
Objective	Key Action Steps	Evaluation Methods	Person Responsible
Objective 6: By August 30, 2003, APIAHF will strengthen individual jurisdictions' HIV services through on-going capacity-building assistance provision	6.1 work with each jurisdiction regarding needs identified through needs assessment Goal I Objective 2 by February 28, 2002 6.2 provide capacity-building assistance as needed	6.1 Completion of work plan developed through Objective 1 by March 31, 2002. 6.2 Annual process and outcome evaluation of work plan completion by end of September 02, and 03.	6.1 Regional Coordinator, to be hired, Prescott Chow, Program Manager, APIAHF and other CBA providers 6.2 Regional Coordinator, to be hired, Prescott Chow, Program Manager, APIAHF and other CBA providers
Objective 7: By August 30, 2003, APIAHF will enhance the region's capacity to provide HIV early intervention services through the development of internal resources in each jurisdiction.	7.1 identify internal resources development areas for each jurisdiction by December 31, 2001 7.2 prioritize equipment to enhance internal resources for each jurisdiction by March 30, 2002 7.3 training as necessary	7.1 Create priority list of resource enhancement plan by December 2001. 7.2 – 7.3 Purchase equipment and based on needs identified conduct trainings by April 30, 2002.	7.1 Prescott Chow, Program Manager, PIJAAG 7.2 Prescott Chow, Program Manager, PIJAAG 7.3 Regional Coordinator, APIAF and other CBA providers



## ATTACHMENT B

### NEEDS ASSESSMENT DATA FORM – HIV PLANNING AND CAPACITY BUILDING GRANTS Ryan White CARE Act, Title III

**Service area/community that you propose to serve:** *American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam, Republic of the Marshall Islands, and the Republic of Palau.*

**1999 population of service area:** *American Samoa: 65,446 (CIA 2000 estimate)*

*CNMI: 79,429 (Department of Commerce/Division of Statistics)*

*FSM: 133,144 (CIA 2000 estimates)*

*Guam: 154,623 (CIA 2000 estimates)*

*RMI: 68,126 (CIA 2000 estimates)*

*Republic of Palau: 19,129 (Republic of Palau 2000 census)*

**TOTAL:** *519,897*

**1. Number of reported cases of AIDS in 1999:** *10*

**Number of reported cases of AIDS in 1998:** *11*

**Percent increase or decrease in AIDS (1999 cases minus 1998 cases, divided by 1998 cases x 100):** *-9.09%*

**2. Number of known HIV-infected persons in the service area/community and/or the estimated number of HIV-infected persons in the service area/community:** *98+*

**Projected number of HIV-infected persons in the service area or community during the year:** *860+*

**3. Surrogate markers for HIV infection:**

**Number of reported cases of gonorrhea in 1999:** *462*

**Number of reported cases of gonorrhea in 1998:** *448*

**Percent increase or decrease in gonorrhea (1999 cases minus 1998 cases, divided by 1998 cases x 100):** *3.13%*

**Number of reported cases of syphilis in 1999:** *201+*

**Number of reported cases of syphilis in 1998:** *330+*

**Percent increase or decrease in syphilis (1999 cases minus 1998 cases, divided by 1998 cases x 100):** *-39.1%*

**STATE SOURCE(S) OF DATA:** *DPH / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau. Additional information from CNMI Department of Commerce/Division of Statistics, Republic of Palau 2000 census, PAETC 2000 Report, OIA 1999 Report, OIA Fact Sheets, CIA World Factbook 2000, AusAIDS Strategic Plan, and Title II Applications / American Samoa, CNMI, FSM, Guam, RMI, and Republic of Palau*

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## PIJAAG CASE STUDIES AND GENERAL INFORMATION

### Testing Positive in the Pacific Island Jurisdictions:

#### American Samoa

No one has tested positive in American Samoa yet. When someone comes in for testing, there is a separate office. The person receives pre-test counseling and then goes to lab for the blood draw, they are given a slip with only a number (to ensure confidentiality). The lab chief is the only one to look at the results. For post-test counseling and test results, the person does not have to come in to the office, it can be done off-site so no one knows. The test requires consent and must be sent with the lab slips - this is all on one page (signature and lab slip, so they know what they are signing).

If someone were to test positive, he or she would first come in for post-test counseling. Within the session, they would be asked to name their sexual contacts for last six months and location, etc. - and the contacts are followed-up. The contacts are told that someone who tested positive gave them his or her name, and they are encouraged to come in and get tested. After a person tests positive, the Medical Director of Health is informed without identifying any names. The members from legislature would also be informed that there is a positive case, again without identifying names. If someone tested positive, they would be given an off-island referral through the hospital for treatment. This referral would go through the board at the local hospital.

#### Commonwealth of Northern Mariana Islands

When a test result is HIV positive the patient will be referred to the STD/HIV/AIDS office. The patient receives post-counseling on the results. Partner tracking is initiated. The patient is immediately given an appointment to see the HIV/AIDS Physician. An assessment is done on the patient. The staff does not contact anyone for assistance. In terms of referrals, patients who are USA Citizens or legal residents referred to the Medicaid Office, and patients who are not USA citizens or legal residents will not qualify for Medicaid assistance or medications.

#### Federated States of Micronesia - Chuuk

In the state of Chuuk in the Federated States of Micronesia, an individual who tests positive for HIV is usually as a result of a routine screening (STI, prenatal, pre-employment physical). The positive report is sent to the National HIV/AIDS Prevention program coordinator, Louisa Helgenberger, who is in Pohnpei. Louisa is the person responsible for completing and submitting HIV case report to CDC.

Individuals seeking an HIV test will receive pretest counseling which includes an elicitation of sexual/risk history, date of birth etc. Nurse will explain to the client what and HIV test involves, information about HIV transmission and also offers to answer any questions that the client may have. Blood is drawn, and results of the ELISA test are available on the same day.

If specimen is positive it is sent to Pohnpei where it is then shipped to Australia for Western Blot- it can take many weeks/months until results of WB are reported. Also, if ELISA is positive, they will repeat the test with a new blood sample. While waiting for the WB results, a client will be told that they have two positive ELISA tests and that there is a very strong likelihood that they are HIV positive. The client is also told, that there are no HIV medications available in Chuuk or FSM.

Nurse will also discuss with the client the issue about their sex partners, their need to be tested and whether or not any of their partners are exhibiting symptoms of AIDS at the time. Clients are asked to bring their partners in to the health department for testing and evaluation. If partners are off-island, if enough specific information is known about the individuals then they are initiated for follow up on the



neighboring island. However, it is unlikely that situation can remain confidential, due to the fact that several individuals may see the information on contacts which appear on the follow up form.

If the HIV positive client appears to be healthy, they advise them while WB is being done to practice safe sex, they are also provided condoms, and they are told that the nurse is always available to answer questions as they come up in the future.

#### Federated States of Micronesia - Pohnpei

No one on Pohnpei has tested positive yet. There are HIV+ individuals on the islands, but they were tested elsewhere. If someone did test positive, the counselor would call the client back and provide counseling. Generally, HIV testing is mostly done as a part of other screenings. This reduces stigma. Clients sign consent forms specifically for HIV testing. Rapid tests are done on-island. If the result is positive, the sample is sent to Melbourne, Australia. The turnaround time is one month and specimen protocols for international travel must be followed. People do not usually come back for results; therefore, being called to come back and get results may result in stigmatization. As a result, individuals have little experience providing post-test counseling, even for HIV negative individuals. In addition, no one is a certified HIV test counselor.

In Pohnpei, there are no medical personnel who specialize in HIV disease and medications may not be available; therefore, post-test counseling cannot include many options for treatment and care. Post-test counseling can include informing the client of the positive test result, and asking for contacts for partner notification. Only the tester has access to files, but in a small community, it is hard to hide when one seeks health screening.

#### Guam

In Guam, there are anonymous and confidential HIV testing sites but most people access confidential sites. The anonymous sites are not seen as truly anonymous because of the small population on the island. HIV has been reportable in Guam since 1988. Contact information is collected in which the client helps identify any sexual and/or substance use partners. Also additional investigation occurs with anonymous sex partners or additional sex partners the client of the DOPH is unable to locate. If a person tests positive, the individual is referred to a primary care center:

- ξ If the person is uninsured, he or she goes to Medical Social Services and gets referred to the public health special infectious disease physician
- ξ If the person is insured, he or she is referred to private physicians, private clinics and/or HMOs. The public health special infectious disease physician also consults with the private clinics and HMOs.
- ξ If the person is underinsured, a worker checks to see if he or she qualifies for state public insurance (MIP -Medical Indigent Program), MEDICAID, or MEDICARE.
- ξ If the client is underinsured and working, he or she may qualify for the Ryan White Title II - ADAP program which Guam Department of Public Health is the main grantee. \*The Guam ADAP Program has been implemented in 2001 and offers nutritional supplements, gas coupons (for transportation), counseling services for individuals, affected families, and some psychiatric services. The ADAP program DOES NOT offer case management services.

For a client going into public primary care services, he or she usually goes to the Southern Region Health Center, where there is a physician who has background in treating HIV-positive patients. At the clinic, the client with the physician can make medical decisions about his or her care. At the Southern Region Health Center, (on island) lab work can be ordered for viral load and t-cell count. There is a lab on island to do testing (ELISA and Western Blot). If the client is uninsured or underinsured, the testing is covered under



MIP. Guam is also in contact with most DOPH in the neighboring islands and is able to refer clients to available services off island. There are currently no case management programs or support groups available. If the client needs family crisis counseling, they can receive counseling through medical social services, but it is general, not HIV specific, therefore providers are not trained to serve HIV-positive clients and their families. This is the same with other public social, primary care and mental health services.

#### Palau

In Palau, four people have tested positive. The first case of HIV in Palau was a middle-aged man. Not much known on the history of this individual (how he contacted HIV, where he contacted HIV). The second case of HIV was identified in 1999. This individual was an MSM Intravenous Drug User who was infected in the U.S. He has been living in Palau for the Palau five years. He did not know he was infected until he checked into a hospital in Palau. No treatment was available for this individual. He made a taped video biography about his life. Before he was tested, he was showing some symptoms of HIV. He suspected that he had HIV, since he was showing symptoms. After he had been tested, he had two serious relationships (but he did not have any sexual contact with these two individuals).

The third case of HIV in Palau was a pregnant female who was diagnosed in 2000. Her HIV diagnosis was picked up through prenatal screening. Her specimen was sent to Hawaii to be tested, and the Eliza/ Western Blot test confirmed that she was positive. There was a three-week turn around time for the result of the HIV test. She had a cesarean section—it is not known if the baby is HIV positive. There was medicine available for this woman through YAP. The fourth case of HIV in Palau was a woman in her early 40's, and was a contact of a contact of the third case in Palau.

Individuals who test positive for HIV are asked to bring in their contacts to the clinic or health department within a certain number of days. If the individual cannot find their contacts, the health department will go into the community and try to find them.

#### Issues of Confidentiality:

##### American Samoa

The island is so small, and everyone knows each other. Everyone sees anyone coming into the office, especially in the waiting room - there is no individual waiting room for people getting tested and there are no doors to the waiting room. Everyone knows the HIV/AIDS office and if they see anyone, they know they are there getting a test.

##### Commonwealth of Northern Mariana Islands

Patient Confidentiality is the most protected commodity in the STD/HIV/AIDS office. It is mandatory for new staff to sign a "Statement of Confidentiality" on their first day at work and every 12 months. Prior to signing the "Statement of Confidentiality" the Supervisor walks through the statement with the new or currently employees and encourages questions. All positive HIV patient medical records are kept in locked files.

##### Federated States of Micronesia - Pohnpei

A white man who had visited the island tested positive when he returned to the U.S. Mainland. He called the emergency room in Pohnpei and informed a nurse of his test result and the name of a woman on the island with whom he had sex. The nurse who took the call did not maintain the woman's confidentiality. The woman was asked to come in to get tested. Over several months, she was tested three times. She felt harrassed and threatened to sue the hospital. The news spread throughout the island that she was positive. In fact, she never tested positive, but the stigma stuck. This incident occurred two years ago.

## Guam

Sometimes the provider knows that a client, or HIV-positive person, is leaving the island. The challenge is trying to link them to care in other islands without breaching their confidentiality, and making sure they are accessing the services available. Right now, Guam is contacting providers on other islands about potential new clients without revealing the name or any other identifying information. Right now there are no MOU's or confidentiality agreements between island nations that would enable to share information about clients and refer clients to services.

In order to begin offering a continuum of care (by Pacific Island Jurisdiction or regionally) a referral system that includes guidelines on sharing medial and confidential information should be implemented.

There needs to be a continuum of care on each island nation as well as regionally. Right now the exchange of information is very limited and many people get lost when they travel or migrate to the different islands. Sometimes clients get re-tested on different islands. There is no way of knowing if someone is getting tested multiple times at different testing sites.

## Palau

This is Palau's definition of confidentiality: Everyone knows about it (HIV cases), but everyone agrees not to talk about it. Since the population of Palau is approximately 19,000, it is hard to keep any information related to who gets tested for HIV, and who seeks HIV treatment confidential. Any results of HIV tests that are done at private clinics are sent to the Palau Health Department.

## Community Issues

### American Samoa

The community is so small. There are some language issues in working with the community: there is a common language and polite/proper language in Samoan - there is no word for vagina in the polite language. People do not talk about sex. Education is also an issue: during teen pregnancy month, counselors were discussing that should not tell teens to use condoms, because telling them to use condoms would be saying that it is okay to have sex. In the health department, they believe prevention is better than cure. If they are going to have sex, we should discuss, HIV prevention and pregnancy prevention.

## Palau

Some community leaders want the names of people who are infected in Palau to be published in the media. If foreigners in Palau (non citizens of Palau) test positive, there is talk among some community leaders that those foreigners should be deported.

There is a misconception that foreigners are primarily responsible for coming into Palau and bringing the disease. However, the reality may be that many individuals indigenous to Palau are bringing the virus when visiting other countries and returning back to Palau. There is much inter-island travel—many individuals in Palau can travel to other jurisdictions and potentially spread the disease.

## Political Implications and Issues

### American Samoa

Political representatives have talked about passing a law to not let anyone with HIV enter American Samoa. They feel that if there were HIV/AIDS cases - we have another island they could go to and can leave them there. For some politicians, there is a sentiment that there are no PLWA's there and they don't want them there.

## Commonwealth of Northern Mariana Islands



If the HIV positive patient is a non-resident alien worker the employer needs to be notified. The CNMI implemented a law and regulation that specify that non-resident alien worker who is found with HIV positive (ELISA and Western Blot) will either return home voluntarily or be deported by the Department of Labor and Immigration. For residents from the Freely Associated States (FSM, Marshall and Palau) who are HIV positive they will not be eligible for Medicaid assistance. However, the Department of Public Health's HIV/AIDS Physician can still provide them services.

#### Federated States of Micronesia - Pohnpei

People who tested positive in Guam or elsewhere may come back home to live (or die). They usually keep their status a secret and usually cannot get medical care. The health department sometimes knows they are on island, but not officially. Politicians have pressured the health department to find out who they are so they can be deported.

#### Palau

Health professionals need to work closely with key individuals working in the government. If somebody tests positive in Palau and moves to Guam, should Palau report the individual to the health department in Guam? How do we track individuals who migrate frequently between islands? Are we opening up a whole can of worms if we break the confidentiality of the individual from Palau by reporting their HIV status to the health department in Guam if he/she moves there?

#### *Challenges for Persons Living with HIV in the Pacific Island Jurisdictions:*

##### American Samoa

There needs to be education within the family and the whole community. For example, people have blocked the road leading to the house of a person living with HIV, so that no one can go see the person including their caregivers (clinicians, nurses, etc.). There was also a case where a Tongan man living with HIV lived next door to his family, and the family went to the immigration office to try to get him deported! The Health Department intervened proving that there was no cause for deportation.

##### Commonwealth of Northern Mariana Islands

In early to mid-last year (2000), an HIV positive individual from Guam visited the STD/HIV/AIDS office. Being focused for the past 15 years on prevention, the STD/HIV/AIDS office was not ready to provide care services to the patient. However, the staff was very accommodating and compassionate with the patient. Being new on the island the staff took the patient to his wishes, food stamp office, Medicaid, housing program, the utility office, etc. The staff also accommodates the patient in their home, gave him some money, (since he came to Saipan broke!) took him grocery shopping. The patient was also introduced to local HIV positives for support. CNMI does not have a support house or group addressing PLWH/A.

After a week the patient started demanding services and comparing CNMI with the States. The patient spent all of his money and had no place to stay. DPH went out to help him stay for a few days in the hospital. On the first night he started harassing and creating problems with the Nurses. The patient got interviewed by a local newspaper and ridiculed the staff of DPH and that if only he has an airline ticket will go back to San Francisco. One kind-hearted person provided his one-way ticket fare. Therefore, the CNMI DPH was not ready to provide the needed services for PLWH/A, but our island and home is open to anyone provided that kindness is returned from the recipient.

##### Guam

Counselors work with person living with HIV to first understand what being HIV-positive means and also to get them into health care. For the clients who are not from Guam, the counselor tries to help them prepare to return home and refer them to services in their home without breaking confidentiality. For all clients,

there is extreme isolation and lack of systematic support. The client has the counselors and staff at DOPH, the physicians, and hopefully some friends and family but the client does not have case manager or mental health services to help with coming to terms with her/his status, treatment and care advocacy, navigating the healthcare system and coping with issues of disclosure, death, illness, and support. Some people 'fall through the cracks' because they may not qualify for services.

#### Palau

A client in Palau had a baby while she was infected with the HIV. She is concerned with finding a job in Palau—the community is very small, and she does not know who knows about her HIV status. She knows that there is documentation of her HIV status in her medical chart at the health department. However, she is constantly in fear that someone will access that chart record, and she wonders how long it will take till someone finds out.

Sustainability of funding for treatment is a big issue in Palau. As the number of cases increase in Palau, it is imperative that Palau received increase funding for prevention and treatment to halt new infections in the region. However, there are many competing priorities in Palau that may hamper increased funding for HIV prevention and treatment. Tobacco, diabetes, and hypertension are more significant health problems in the region, and affect a great percentage of Palau's inhabitants. HIV is something that is not as rampant as those diseases, however, it is crucial that preventative measures be implemented before Palau, as well as the Pacific Region, starts to develop more and more cases of HIV.

#### Testing Challenges

##### American Samoa

In American Samoa, people do not want to know if they have HIV or not. They would rather live with it and not deal with it. They do not think that they will spread it. They will have to follow-up with people who have tested. Many people call and want telephone results (which could be anyone and not the person who was actually tested - cannot ensure confidentiality), but they are asked to come in.

There are serious lab issues. It takes **several months** for the first test result to come in. The lab in the hospital is the authority. All specimens are sent to Honolulu. In addition, the local hospital lab often keeps the specimens too long - once they become too old and the person needs to be tested again. Also, the machine was broken for months and there were problems with reagents being expired. They have recently gotten a new machine; however there is no technician who is trained to do the testing. Thus, the specimens continue to be sent out, which increases the lag time. If someone would be trained in using the machine, they could run samples on island. Since no one can use the machine, donated blood is not being screened. Potential recipients sign a waiver indicating that they understand that the blood received is not screened and so they cannot sue later. Since there haven't been any cases, people do not see this issue as important.

#### Requested Trainings and CBA needs

##### American Samoa

- ξ Basic HIV information in-service training for CPG
- ξ Next phase of the AIDS ETC education trainings
- ξ Trainings on working with individuals who test positive
- ξ Creating a connection between care and prevention services (since there is a disconnection currently because care and prevention services at DOH are independent)
- ξ Confidentiality training for clinicians

##### Commonwealth of Northern Mariana Islands

- ξ Training of trainers is paramount - cross training is a must for all prevention and care staff.



- ξ Training is basically needed for "certification in pre/post counseling".
- ξ Training for clinical staff on the care/clinic aspects for PLWH/A.
- ξ Training for Case Managers (Management) working with PLWH/A
- ξ Training of PLWH/A to support of other PLWH/A
- ξ Training of Public Health Nurses on Home Care
- ξ Training of CPG's role in community activities.

#### Federated States of Micronesia - Pohnpei

They have 1 nurse and 1 physician going through the Pacific AETC clinical training program. They need to be encouraged to continue the program and, once completed, need additional support. No one is certified to provide HIV prevention pre and post test counseling. Need training in data management and reporting. CPG members do not know what they are supposed to do. They are supposed to meet 4x per year, but are pretty inactive. There is some STD infrastructure, but they are stretched too. They need better options for testing and sending specimens. They use 3000-4000 tests per year.

#### Guam

- ξ HIV prevention, HIV counseling and testing - linguistic and cultural competency, one-to-one and small group interventions and counseling techniques
- ξ CBO medical training, provider training
- ξ Understanding case management
- ξ Regional training on standardizing CDC guidelines

#### Palau

- ξ Training on HIV testing for more personnel in the labs (currently there is a dearth of individuals who know how to work the equipment in the labs to test for HIV)
- ξ More HIV testing equipment
- ξ Better protocols are needed for counseling and testing - update CDC counseling and testing protocols to be culturally and geographically appropriate to Palau and the Pacific Island region
- ξ More training for peer health educators in Palau

#### *Most Needed Care Services in the Pacific Island Jurisdictions*

##### American Samoa

- ξ Case management
- ξ Home health care by professionals
- ξ Medications

##### Commonwealth of Northern Mariana Islands

- ξ Funding for medications

#### Guam

- ξ Case management
- ξ Primary care providers and services
- ξ Support group

#### *Most Needed Prevention Services in the Pacific Island Jurisdictions*

##### American Samoa

- ξ Education, specifically community education
- ξ Better lab services - labs currently do not get specimens out in a timely fashion
- ξ Mandatory measures for labs where specimens get out immediately

- § Train DOPH staff to do their own lab do screenings (there is already a facility at DOH for lab work, but no one is using it)

#### Commonwealth of Northern Mariana Islands

- § Additional funding for test kits (Ora-Sure). Increase funding on trainings mentioned above.

#### Guam

- § To reach underserved communities living in Guam
- § Support and education on issues of sexuality, sexual orientation
- § Information and advocacy on health access
- § Public info campaigns on HIV awareness that is culturally/linguistically appropriate.
- § Increase and link services on suicide prevention, substance use, mental health services

#### Systems that Need to Be Put into Place

##### American Samoa

- § Connection between care and prevention
- § Individuals trained ahead of time to deal with someone testing positive, for medical social services, nutritionists, doctors, clinicians, etc.
- § System of care for when someone tests positive.

#### Commonwealth of Northern Mariana Islands

- § CBA network for Pacific Island Jurisdictions with Pacific Island experience.

#### Guam

- § Technological systems: computers, email, reporting software
- § Regional and local tracking system with HIV, STDs, and other co-factors such as substance uses, etc.
- § Regional referral system and information/records sharing system.

#### How PIJAAG Can Help

##### American Samoa

PIJAAG can be a forum for sharing information and problems among the islands - discussing what works and what has not, so members can see what works on other islands and try to apply that to their own islands. Many of the problems seem similar in the jurisdictions - they can problem solve together. Guam seems so far ahead - they want to be able to call each other and find out how they can deal with what's happening, especially if they have already dealt with it on their island.

#### Commonwealth of Northern Mariana Islands

- § To continue to be visible and viable. Continue to be a strong advocate for prevention and care (CDC & HRSA) services.

#### Guam

- § Maintain and sustain the work it is already doing and plans to do
- § Get more states involved, i.e. every state in FSM, Marshall Islands
- § Set up a system of PIJAAG support such as other people who are doing similar or related work: Other government offices, peace corps, American red cross, churches, CBO's, community leaders.
- § Look at the system in a multi-sectoral approach



## Notes



## **HIV/AIDS in the U.S. Affiliated Pacific Island Jurisdictions**

**Vincent Crisostomo**

**George Washington University**

**Submitted to : The Community Psychologist**

***February 2003***

This paper, will provide a brief overview of HIV/AIDS in the U.S. affiliated Pacific Island Jurisdictions (PIJs) which are comprised of three U.S. territories and three U.S. freely associated states. U.S. territories include American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI) and Guam. U.S. freely associated states include the Federated States of Micronesia (FSM), the Republic of the Marshall Islands (RMI), and the Republic of Palau. Contemporary histories of the Pacific Island Jurisdictions are complex, with legacies of colonization by Spain, Germany, Japan, as well as the U.S. The current U.S. involvement in the region is equally complicated; issues of self determination, land rights, federal dependency, U.S. military presence, nuclear weapons testing and related illnesses, immigration policies, and labor conditions continue to dominate this relationship.

The year 2001 saw these island States and Territories presented with their first indigenous HIV/AIDS cases, however the low numbers of HIV reported cases do not show the true number of HIV cases in the jurisdictions and the extent of the burden of care that HIV services pose on the jurisdictions. There still exists a denial in the jurisdictions that HIV/AIDS is in the community and a denial of the possibility that one is at risk (*PIJAAG February meeting*). People may test HIV positive off island but later return home in the late stages of the disease. This is especially true for Pacific Islanders, where the cultural and linguistic, as well as familial ties, bring many People Living With HIV/AIDS (PLWHA) home when they become sick and require care (*Pacific AIDS Education & Training Report 2000*). The main barriers for PLWHAs in the Pacific Island Jurisdictions are the lack of a continuum of HIV care services in each jurisdiction and the lack of coordinated care services in the region. PLWHA may not be accessing

services because, in most jurisdictions, there are no services to access. The lack of coordinated HIV care services throughout the region has repeatedly been reported as a barrier to care with migration throughout the region. In the sections that follow I will present information that includes an overview of HIV, HIV Prevention and Care Services and finally some successful recommendations and strategies developed and implemented by service providers from all six PIJs with assistance from the Pacific Island Jurisdictions AIDS Action Group (PIJAAG). The information is drawn from a needs assessment conducted by the University of Hawaii affiliated Pacific AIDS Education & Training Center (PAETC), a Capacity Building proposal submitted to the Health Resources & Services Administration (HRSA), and notes and minutes from the face to face meetings of the Pacific Island Jurisdictions AIDS Action Group (PIJAAG).

## **HIV/AIDS**

Though there are only a few reported cases of HIV/AIDS, the projections of HIV in the region are high in relation to population size. For example, in American Samoa, six PLWHA, not tested in the islands, came to American Samoa with end-stage AIDS (*PAETC report 2000*). However, this is not reported as AIDS cases in American Samoa and officially at the end of 2000, the island has "zero" AIDS cases unfortunately the year 2001 saw all of the Pacific Island Jurisdictions presented with their first indigenous HIV infections. One or two HIV/AIDS cases in an area that lacks the infrastructure in their healthcare systems to provide the proper support can quickly drain the resources that an island community has available to access.

HIV/AIDS cases in the jurisdictions are primarily in Pacific Islander and Asian populations. 1999 AIDS cases in Guam shows that 72% of the cases are Pacific Islander

or Asian; this population also accounts for 60% of HIV cases that year. In 2000, Guam's seven new cases include five Chamorro/Guamanian and two FSM citizens. CNMI's cumulative HIV/AIDS cases through 2000 indicates that 95% of PLWHA are Pacific Islanders or Asians. Previously, HIV has not been a high priority for local health care providers because there are so few cases and because the medical systems are already overloaded by: diabetes, hypertension, coronary heart disease, and TB. HIV projections may be a more accurate way to describe the potential burden of care each jurisdiction will face.

The subpopulations at highest risk for HIV/AIDS, varies in each jurisdiction. In Guam, for example, Men having Sex with Men (MSM) continue to be the group at highest risk for HIV/AIDS, comprising 70% of HIV cases and 63% of AIDS cases in 1999. Both injecting drug users and heterosexual men and women accounted for 10% of new HIV cases (*Guam Title II application*). While historically MSM were the highest risk group in CNMI, the epidemiology has been changing to include women, teenagers, and newborn babies. Cumulatively, heterosexual men comprise 29% and heterosexual women comprise 29% of the HIV cases in CNMI (*CNMI Title II application*). Most of FSM's HIV/AIDS cases are among the male population (FSM Title II application).

### **HIV/AIDS SERVICES IN THE PIJs**

A detailed investigation is needed to understand the full scope of the situation in the region. While all jurisdictions are providing HIV prevention interventions to their local populations, there is much variation in the thoroughness of those interventions. For example, FSM is providing HIV antibody testing (in Chuuk), but doesn't have the current capacity to provide pre- and post- test counseling, a critical component of all HIV



prevention strategies. Also, testing in FSM is not available in every state and is inaccessible because of transportation, time, and cost to travel inter-island. Testing itself has been an issue, as lab work needs to be sent off island to Hawai'i or Australia; FSM and Palau have experienced problems with the only air carrier for the region, Continental Micronesia, which refuses to transport "infectious agents", even if the specimens are properly packaged. Other problems include the time it takes for the test results to be returned; in American Samoa, there are only two flights a week (Mondays and Fridays) and tests may take 4-6 weeks to be returned. In at least one instance, results took 2 months (*PIJAAG April 2001 meeting*). Currently, only Guam and FSM (Chuuk) has lab facilities on-island to conduct Elisa tests. However, all Western Blot confirmatory tests must be sent to Hawai'i or Australia. Safe blood supply is also an issue for some of the jurisdictions, with both FSM and American Samoa currently not screening donated blood (*PAETC 2000 Report and PIJAAG February 2001 meeting*). This is due to the lack of equipment and staff training to test the supply.

HIV care services fairs much worse, with only Guam currently offering HIV-specific primary care services to PLWHA. Guam is able to provide CD4 counts and viral load testing; other jurisdictions cannot. Guam also has funds for drug therapies; the other jurisdictions do not. However, Guam is limited in its resources and cannot offer early intervention or case management services. With this gap, Guam is NOT able to provide client-centered services to link individuals with primary health care, psycho-social and other services in a timely manner; provide on-going assessment of the client's needs, and development of a service plan. Guam's health department does work closely with the only AIDS service organization in the region, Coral Life

Foundation, to provide some limited HIV care services (through foundation money) and HIV prevention, but the resources are minimal.

CNMI has some of the infrastructure to provide primary health services to PLWHA, though not specifically HIV primary care. There is some coordination plans with other federal services as well as linkages with prevention and substance use programs. Recently, the HIV/STD Program has been given a government building that in the future will be a center for PLWHA support activities.

The Republic of Palau is in the early stages of development, with no specific HIV care services currently in place. With 2 new cases in 2000 and 2001, Palau is facing difficult situations because of the lack of HIV care service infrastructure. Medications have been initiated to prevent prenatal transmission for an HIV positive pregnant woman; however, the treatment was initiated without baseline CD4 counts and viral load testing, currently unavailable in Palau. Blood specimens, as previously mentioned, aren't accepted by the only airline carrier in the region. Medication for this woman had to be borrowed from another jurisdiction. Provision for future treatment of PLWHA in Palau is still not clear (*Palau Title II application*). American Samoa, RMI and FSM currently do not have HIV care services and are in the process of its development. Both RMI and FSM do not have funds for medication (and are ineligible for Medicaid programs). Currently in FSM, the only treatments available to PLWHA are antibiotics and intravenous fluids (*PIJAAG April meeting, FSM Title II application*).

## **FUNDING FOR HIV PREVENTION AND CARE SERVICES**

In 2001, all jurisdictions began receiving HRSA Title II Funds at the baseline amount (\$50,000) for HIV care services, these monies are specifically designated to

serve PLWHAs and based on a formula. Additionally, Guam receives some AIDS Drug Assistance Program (ADAP) funds. Each jurisdiction also receives Center for Disease Control (CDC) funds for HIV prevention activities; 5 of the 6 also receive Division of Adolescent School Health (DASH) funds. DASH funds the Youth Risk Behavior Survey which measures priority health-risk behaviors among youth, including HIV/STDs.

Coral Life Foundation, a community based organization in Hagatna, Guam and the only cbo funded to do HIV/AIDS work in the PIJs, received funding through the Guam Department of Public Health, through CDC, and through private foundations like the Gill Foundation and Mac Cosmetics. Unfortunately, after a number of setbacks, CLF has had to limit operations in recent months.

Each jurisdiction will continue to develop its HIV care services through their newly awarded Title II funds. However, these jurisdictions being newly funded will need on-going assistance to ensure each jurisdiction is able to provide a continuum of HIV care services appropriate to their area. At their base funding of \$50,000 per year, this is hardly enough to support a continuum of HIV care services.

## **RECOMMENDATIONS**

The Guam Conference Report from the University of Hawai'i on its recent HIV/AIDS conference held in January 2001 for physicians, nurses, and other health care professionals in the Pacific Island region identified five areas of need for the management of HIV in the jurisdictions.

1. Communication among the jurisdictions needs to be improved, including the sharing of information about migrating PLWHA throughout the region. The group suggested a tracking mechanism, but realized the complexity of coordination and

protection of client confidentiality. Communication between the regions also would help peer-to-peer support.

2. Communication and support within each jurisdiction is needed to coordinate HIV care services.
3. The jurisdictions need to have access to information from outside the region.
4. Training for health care providers and the community-at-large on the continuum of HIV related issues and community mobilization strategies are needed.
5. Funding for programs, training, and medications is needed (*University of Hawai'i Guam Conference Report*).

The findings from this report are similar to an assessment by the San Francisco based Asian Pacific Islander American Health Forum who proposed a project in June 2001 to the Health Resources & Services Administration (HRSA). This project would provide a unique regional approach that can more effectively and efficiently address the lack of HIV care services in the jurisdictions. The project done in collaboration with the Pacific Island Jurisdictions AIDS Action Group (PIJAAG) proposes to build HIV care service delivery capacity of the region, through overall regional activities coordination, regional capacity-building assistance, as well as one-on-one capacity-building with each of the jurisdictions. The project will 1) increase coordination and collaboration between the jurisdictions, 2) develop and support HIV training and technical assistance in the region, and 3) work with each jurisdiction to develop capacity for baseline standard of HIV care services. Objectives include yearly training to increase capacity to serve HIV clients, standardized policies and procedures for the region to ensure client confidentiality and rights, enhancement of each jurisdictions' internal infrastructure to



provide services, and the development of a shared medical records system between the jurisdictions. Sharing resources in the region will be critical in ensuring all PLWHA will have access to HIV primary care services, early intervention, and case management. This proposal ambitious, as it is, was submitted to HRSA in June 2001 and while it made an acceptable grade as of February 2003 has yet to be funded.

PIJAAG through its successful advocacy efforts has seen CDC increase prevention funding to the PIJs by \$600,000 and create an HIV Prevention Community Planning Guidance that is sensitive to the resources and current infrastructure of each PIJ. PIJAAG will also convene their first regional HIV/AIDS conference on Palau in Spring 2003. Currently the results of similar advocacy done with HRSA are in development. The efforts behind Guam's HRSA funded Title III Planning Grant for PLWHAs to Access Primary Care resulted in the creation of the Guam System of Care Services (SOCS) For People Living With HIV/AIDS (PLWHAS). SOCS recently held a consortium in February 2003 which resulted in a Mission Statement and 13 PLWHAS stepping forward to advocate and raise awareness of their needs.

## **IN CLOSING**

Often neglected, the PIJs welcome these successes while at the same time embracing the challenges that HIV has brought to their island communities. The collaborative efforts of their service providers done in conjunction with PIJAAG, nationally funded capacity builders like APIAHF and Federal supporters sensitive to their needs is just beginning. The impact that HIV will have in the PIJs remains to be seen.





Notes

Lined paper for notes with horizontal ruling lines.



### Overall Conference Goal

This conference is seen and hoped to be a first of a series of conference to increase information and capacity for HIV prevention and care in the US Affiliated Pacific Islander Jurisdictions. The sharing that will take place amongst and Pacific Island Jurisdictions will set the stage for further collaboration and capacity building assistance within the Pacific Island Jurisdictions as well as the US mainland.

This conference hopes to provide some ground work around issues relating to efficient and effective utilization of HIV funding through:

- Identification and targeted service provision strategies to reach the high-risk communities in the Pacific Jurisdictions
- Create systems and methods of providing HIV counseling, testing and referral in a way that meets the needs of high-risk communities
- To understand the processes and importance of creating a HIV Prevention Community Planning Process that includes the realities of the Pacific Island Jurisdictions.

### Day One- Focus on Populations at Risk

**Goal:** To understand the importance, challenges, and successes of identifying high-risk communities and providing programs targeted to high risk communities in the Pacific Island Jurisdictions.

#### **Objectives:**

1. To understand the definition of high-risk communities and how to identify them
2. To understand the strategies to provide comprehensive services targeted to these subpopulations.
3. To understand the unique challenges of identifying and providing services to high-risk communities in the Pacific Island Jurisdictions

Time	Agenda	Learning Objectives At the end of each session:	Suggested Speakers
9:00 am	Welcome, overview, and cultural	ξ To welcome participants to Palau	Johana

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	opening		<p>ξ To give overview of PIJAAG</p> <p>ξ To set tone and expectations for the next three days</p> <p>ξ To connect HIV work with the work of community health and wellness work that is done through culture</p>	Ngiruchelbad (Palau), Xuan Lan Doan (Hawaii) and Dr. Caleb Otto (Palau)
<b>10:00 am</b>	Plenary I: How to determine who is at risk for HIV and how to provide them with targeted services		<p>ξ To understand theory of identification and definition of high-risk groups in PI communities – why it is important and how to do it.</p> <p>ξ To understand theories to translate knowledge of high-risk communities into development of comprehensive community-specific HIV prevention.</p>	Maire Bopp (Cook Islands) David Lowrance (CNMI)
<b>11:10 am</b>	Break			
<b>11:20 am</b>	Break-out Group I: High-risk Population Identification-Challenges for the Pacific		<p>ξ Participants will discuss the unique challenges to identify and define subpopulations in PI communities and to develop effective HIV prevention.</p> <p>ξ Participants will discuss strategies to address these unique challenges.</p>	-Participants will go through a facilitated dialogue with questions. -Participants will be randomly broken out into groups
<b>12:20 pm</b>	Presentation of Summaries by Groups		ξ Participants will report back their discussion and lessons learnt	
<b>12:50 pm</b>	Lunch			
<b>1:50 pm</b>	Plenary II: How to Develop HIV Prevention Targeting High-Risk Populations.		ξ Participants will understand applied techniques to develop and implement a comprehensive community-specific HIV prevention strategy	Mike O'Leary (Guam), Mike Manglona

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			based on understanding of and emphasis on high-risk groups. ξ Case Study(ies) on how this was done in some Pacific Island Jurisdictions will be presented	(CNMI)
<b>3:00 pm</b>	Break Out Sessions: High-Risk Populations- Practical Applications to Identification and Service Provision	ξ	ξ Discussion of applicability and limitations of these techniques of High-Risk population identification in specific PI communities. ξ Discussion of strategies to address and circumvent limitations	Participants will be divided into the Pacific Island Jurisdictions.
<b>4:15 pm</b>	Presentation of Summaries by Groups	ξ	ξ Participants will present back on discussion and lessons learnt.	
<b>4:45</b>	Closing Remarks and Evaluation	ξ	ξ Participants will be reminded of the days to come. ξ Participants will be asked to complete evaluations for Day 1	Xuan Lan and Hana
<b>6- 8</b>	Reception	ξ		Palau Govt

**Day Two- Focus on HIV Counseling, Testing and Referral**

**Goal:** To highlight the importance, challenges, and successes of HIV counseling, testing and referral (HCTR) as a strategy to bring clients into prevention as well as care services.

**Objectives:**

1. To understand the goals, principles, and effective models of HIV counseling, testing and referral.
2. To understand testing strategies in low to moderate prevalence areas.
3. To understand the strategies that address challenges of making HIV testing accessible to high-risk populations.
4. To understand the unique challenges and opportunities provided by HIV testing to bring clients into appropriate prevention and care services.

Time	Agenda	Learning Objectives At the end of each session:	Suggested Speakers
9:00 am	Introduction of Second Day's agenda		Hana & Xuan-Lan
9:10 am	Plenary I: HCTR- Basic Principles, Models and Strategies	ξ To understand basic goals of HCTR ξ To understand HCTR's importance as a prevention activity ξ To understand HCTR's importance as a care activity	Bernie Schumann (Guam), Dean Wong (Hawaii)
10:20 am	Break		
10:30 am	Break-out Group I: Challenges and Solutions of Meeting the Goals of HIV Testing	ξ Participants will discuss and identify the unique challenges to HCTR in the Pacific. ξ Participants will discuss strategies to address these unique challenges. ξ Participants will discuss strategies to utilize HCTR as a route of primary early access to care for people living with HIV. ξ Participants will discuss the role that access to care can	-Participants will go through a facilitated dialogue with questions. -Participants will be randomly broken out into



		have in clarifying the benefits of HCTR.	groups
<b>11:30 pm</b>	Presentation of Summaries by Groups	<ul style="list-style-type: none"> <li>Participants will report back their discussion and lessons learnt</li> </ul>	
<b>12:00 pm</b>	Lunch		
<b>1:30 pm</b>	Plenary II: Effective Programs HCTR In the Pacific	<ul style="list-style-type: none"> <li>Markers of Effective HCTR Programs</li> <li>HCTR strategies in low/ moderate prevalence areas</li> <li>HIV testing in special populations (eg: pregnant women, migrant workers)</li> <li>Social marketing campaigns to make HCTR accessible to high-risk communities.</li> <li>Making referrals to HIV prevention and care.</li> <li>The challenges of maintaining confidentiality in providing access to HCTR and care services.</li> <li>Linking HCTR and care with other related STIs and other infectious diseases (like TB) in the Pacific.</li> </ul>	Naseri Aitaoto (American Samoa), RMI Clinician (Dr. Tin Soe), and Eleanor Sos (Federated States of Micronesia)
<b>2:40 pm</b>	Break		
<b>2:50 pm</b>	Break Out Sessions: High-Risk Populations- Practical Applications to Identification and Service Provision	<ul style="list-style-type: none"> <li>Participants will discuss the challenges and strategies to get more people into testing through traditional and non-traditional testing sites.</li> <li>Participants will discuss strategies to make HCTR accessible to high-risk communities</li> <li>Participants will highlight marketing campaigns that have made HCTR accessible in the Pacific</li> <li>Participants will discuss the challenges and strategies to successful referrals to prevention and care services</li> </ul>	Participants will be divided into random groups.
<b>4:20</b>	Presentation of Summaries by Groups	<ul style="list-style-type: none"> <li>Participants will present back on discussion and lessons learnt.</li> </ul>	
<b>4:50</b>	Closing Remarks and Evaluation	<ul style="list-style-type: none"> <li>Participants will be reminded of the days to come.</li> <li>Participants will be asked to complete evaluations for Day 2</li> </ul>	

**Day Three- Focus on Community Planning**

**Goal:** To enhance Community Planning in the Pacific Jurisdictions.

**Objectives:**

1. To Understand the context of community planning in the U.S. and the Pacific Jurisdictions
2. To Identify and explore barriers to effective community planning
3. To Develop effective solutions to strengthen community planning

<b>Time</b>	<b>Agenda</b>	<b>Learning Objectives At the end of each session:</b>	<b>Suggested Speakers</b>
<b>9:00am</b>	Plenary I: History of Community Planning & New Guidance	<p>§ Participants will state the context and history of community planning in the U.S. and the Pacific</p> <p>§ Participants will describe the new guidance and its potential application to the Pacific region.</p>	Vicky Rayle (CDC) and Josephine O'Mallan (Guam)
<b>10:00 am</b>	Break-out Group I: Exploring Specific Challenges in Community Planning in the Pacific	<p>§ Participants will identify specific challenges to community planning in their local area</p>	-Participants will go through a facilitated dialogue with questions. -Participants will be randomly divided into groups
<b>11:00 am</b>	Presentation of Summaries by Groups	<p>§ Participants will describe challenges in community planning</p>	
<b>11:30</b>	Lunch		
<b>12:30</b>	Mini-Plenary II: Challenges & Successes in Community Planning in the Pacific	<p>§ To provide overview of Challenges and Success of Community Planning in the Pacific</p>	Xuan Lan Doan
<b>12:45 pm</b>	Fish Bowl on Community Planning- Challenges and Successes	<p>§ To examine potential barriers and solutions to effective community planning in their jurisdiction</p> <p>§ To address specific challenges and solutions related</p>	A representative from each Jurisdiction will

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		to- Recruitment and Retention, Training and Leadership, Roles and Responsibilities, and Parity, Inclusion, and Representation on Community Planning Groups	participate in the fish bowl -Peter Tuiolesega Silva (Hawaii) moderator, Edward Taitano (Guam), Goretti Masayos (Palau), Jackie Quitugua (CNMI), Fuela Turituri (American Samoa)
1:30 pm	Break		
1:40 pm	Break Out Sessions: Exploring Specific Strategies to Strengthen Community Planning in the Pacific (possible menu of breakouts: Recruitment & Retention; Parity, Representation & Inclusion Issues, Leadership Development, Needs Assessment, Care incorporated into planning etc)	ξ Participants will identify specific strategies to strength community planning in their local area	People choose break out groups according to area of interest.
3:00 pm	Presentation of Summaries by Groups	ξ Participants will apply and adapt successful strategies to strengthen community planning in their local area. ξ Participants will describe ways to strengthen community planning for the future in the Pacific.	
4:00- 5:00 pm	Closing remarks, Closing Ceremony and Evaluation	ξ To build momentum for community planning in the Pacific ξ Do Evaluation for Day 3 and the entire Meeting	TBD





# FIRST PIJAAG SUMMIT ON HIV/AIDS

*building bridges*



*taking action*

April 24-26, 2003

Palasia Hotel

Koror, Palau



The First PIJAAG Regional Summit on HIV/AIDS, hosted by the Pacific Islands Joint AIDS Advisory Group, is designed to increase information sharing, collaboration opportunities and understanding in the Pacific region.

This conference hopes to provide some ground work around issues relating to:

- Identifying and targeting service provision strategies to reach the high-risk populations
- Creating systems and methods of providing HIV counseling, testing and referral
- Understanding the processes and importance of creating a HIV Prevention culture

## DAY ONE THURSDAY, APRIL 24 - POPULATIONS AT RISK

**GOAL:** To understand the importance, challenges, and successes of identifying high-risk communities and providing programs targeted to high risk communities in the Pacific Island jurisdictions.

### **OBJECTIVES:**

1. To understand the definition of high-risk communities and how to identify them
2. To understand the strategies to provide comprehensive services targeted to these subpopulations.
3. To understand the unique challenges of identifying and providing services to high-risk communities in the Pacific Island jurisdictions.

<b>9:00 am</b>	<b>WELCOME, OVERVIEW OF PIJAAG, OPENING CEREMONY</b> Speakers: <i>Vice President and Minister of Health. Sandra S. Pierantozzi (Palau). Johana Ngiruchelbad (Palau), Xuan-Lan Doan (Hawai'i) and Dr. Caleb Otto (Palau)</i>
<b>10:00 am</b>	<b>PLENARY I: HOW TO DETERMINE WHO IS AT RISK FOR HIV AND PROVIDE THEM WITH TARGETED SERVICES</b> Speakers: <i>Maire Bopp (Cook Islands), Dr. David Lourance (CNMI)</i>
<b>11:10 am</b>	<b>BREAK</b>
<b>11:20 am</b>	<b>BREAK OUT SESSION: HIGH-RISK POPULATION IDENTIFICATION CHALLENGES FOR THE PACIFIC.</b>
<b>12:20 pm</b>	<b>PRESENTATION OF SUMMARIES BY GROUPS</b>
<b>12:50 pm</b>	<b>LUNCH (provided)</b>
<b>1:50 pm</b>	<b>PLENARY II: HOW TO DEVELOP HIV PREVENTION TARGETING HIGH-RISK POPULATIONS</b> Speakers: <i>Mike O'Leary (Centers for Disease Control and Prevention), Mike Manglona (CNMI)</i>
<b>3:00 pm</b>	<b>BREAK OUT SESSION: HIGH-RISK POPULATIONS - PRACTICAL APPLICATIONS TO IDENTIFICATION AND SERVICE PROVISION</b>
<b>4:15 pm</b>	<b>PRESENTATION OF SUMMARIES BY GROUPS</b>
<b>4:45 - 5:00 pm</b>	<b>CLOSING REMARKS AND EVALUATION</b> Speakers: <i>Johana Ngiruchelbad (Palau), Xuan-Lan Doan (Hawai'i)</i>
<b>6:00 - 8:00 pm</b>	<b>RECEPTION</b> <i>Sponsored by the Government of Palau</i>

## DAY TWO FRIDAY, APRIL 25 - HIV PREVENTION

**GOAL:** To highlight the importance, challenges, and successes of HIV prevention, referral (HCTR) as a strategy to bring clients into the health system.

### **OBJECTIVES:**

1. To understand the goals, principles, and strategies of HIV prevention and referral.
2. To understand testing strategies in low and high risk populations.
3. To understand the strategies that address high-risk populations.
4. To understand the unique challenges and strategies for bringing clients into appropriate prevention and referral.

<b>9:00 am</b>	<b>INTRODUCTION OF DAY TWO</b> Speakers: <i>Johana Ngiruchelbad (Palau)</i>
<b>9:10 am</b>	<b>PLENARY I: HIV PREVENTION AND REFERRAL (HCTR) - BASICS</b> Speakers: <i>Bernie Schumacher (Hawai'i)</i>
<b>10:20 am</b>	<b>BREAK</b>
<b>10:30 am</b>	<b>BREAK OUT SESSION: HIGH-RISK POPULATION IDENTIFICATION CHALLENGES FOR THE PACIFIC.</b>
<b>11:30 am</b>	<b>PRESENTATION OF SUMMARIES BY GROUPS</b>
<b>12:00 pm</b>	<b>LUNCH (provided)</b>
<b>1:30 pm</b>	<b>PLENARY II: EFFECTIVE HIV PREVENTION AND REFERRAL</b> Speakers: <i>Naseri Aitaot (Palau) and Eleanor Sos (FSM)</i>
<b>2:40 pm</b>	<b>BREAK</b>
<b>2:50 pm</b>	<b>BREAK OUT SESSION: HIGH-RISK POPULATIONS - PRACTICAL APPLICATIONS TO IDENTIFICATION AND SERVICE PROVISION</b>
<b>4:20 pm</b>	<b>PRESENTATION OF SUMMARIES BY GROUPS</b>
<b>4:50 - 5:00 pm</b>	<b>CLOSING REMARKS AND EVALUATION</b>

stand Jurisdictions AIDS Action Group (PIJAAG) is a first of a series of gatherings in the Pacific capacity for HIV prevention and care in the United States-affiliated Pacific Island jurisdictions and the

efficient and effective utilization of HIV funding by:  
high-risk communities in the Pacific.  
and referral in a way that meets the HIV prevention and care needs of high-risk communities.  
ention Community Planning Process that includes the realities of the Pacific Island jurisdictions.

COUNSELING, TESTING AND REFERRAL

and successes of HIV counseling, testing and  
prevention as well as care services.  
  
effective models of HIV counseling, testing  
  
to moderate prevalence areas.  
challenges of making HIV testing accessible to  
  
opportunities provided by HIV testing to  
and care services.

TWO AGENDA

*ibad (Palau), Xuan Lan Doan (Hawai'i)*

ING TESTING AND REFERRAL  
S, MODELS AND STRATEGIES  
*(Guam), Dean Wong (Hawai'i)*

CHALLENGES AND SOLUTIONS OF  
OF HIV TESTING

AMARIES BY GROUPS

E, HCTR PROGRAMS IN THE PACIFIC.  
*o (American Samoa), Dr. Tin Soe (RMI),*

HIGH-RISK POPULATIONS – PRACTICAL  
IFICATION AND HCTR PROVISION

AMARIES BY GROUPS

EVALUATION

DAY THREE SATURDAY, APRIL 26 - COMMUNITY PLANNING

GOAL: To enhance Community Planning in the Pacific Jurisdictions.

OBJECTIVES:

1. To understand the context of community planning in the U.S. and the Pacific Island jurisdictions
2. To identify and explore barriers to effective community planning
3. To develop effective solutions to strengthen community planning

8:30 am	PLENARY I: HISTORY OF HIV PREVENTION COMMUNITY PLANNING AND THE NEW COMMUNITY PLANNING GUIDANCE Speakers: <i>Victoria Rayle (Centers for Disease Control and Prevention) and Josephine O'Mallan (Guam)</i>
9:30 am	BREAK OUT SESSION: EXPLORING COMMUNITY PLANNING CHALLENGES IN THE PACIFIC
10:30 am	PRESENTATION OF SUMMARIES BY GROUPS
11:00 am	BREAK
11:10 am	PANEL ON COMMUNITY PLANNING - CHALLENGES AND SUCCESSES Speakers: <i>Peter Tuiolosega Silva (Hawai'i), Edward Taitano (Guam), Goretti Masayos (Palau), Jackie Quitugua (CNMI), Fuela Tirituri (American Samoa), Joe Commor (FSM)</i>
12:10 am	LUNCH (provided)
1:10pm	BREAK OUT SESSION: EXPLORING SPECIFIC STRATEGIES TO STRENGTHEN COMMUNITY PLANNING IN THE PACIFIC
2:30 pm	PRESENTATION OF SUMMARIES BY GROUPS
3:30 - 4:30pm	CLOSING REMARKS, CLOSING CEREMONY AND EVALUATION Speaker: <i>Dr. Stevenson Kuartei (Chief of the Division of Primary and Preventive Services, Palau)</i>



# Pacific Island Jurisdictions AIDS Action Group

American Samoa  
Commonwealth of the Northern  
Mariana Islands  
Federated States of Micronesia  
Guam  
Republic of Palau  
Republic of the Marshall Islands

In February 2001, the Pacific Island Jurisdictions AIDS Action Group (PIJAAG) formed during a discussion of the state of HIV prevention and care services in their respective jurisdictions. This group, which included AIDS directors, program staff, community stakeholders, as well as federal partners and capacity-building assistance providers, discussed the shared experiences of the Pacific Island jurisdictions.

From these discussions, the group began formulating a regional plan to address HIV/AIDS prevention and care needs. PIJAAG has taken the opportunity to meet during the last 2 years to address current issues and implement its regional plan. PIJAAG has met and has had a presence at the the following gatherings: Community Planning Orientation Training 2001, Community Planning Leadership Summit 2001-2003, Asian & Pacific Islander American Health Forum VOICES Conference 2001, CDC's HIV Prevention Conference 2001, CDC Surveillance Meeting 2002, Global Health Conference 2002, U.S. Conference on AIDS 2002, HRSA All Titles Meeting 2002, API Summit on HIV/AIDS Research Conference 2002, and CDC EPI Profile Training 2003.

## MISSION STATEMENT

We are representatives of the United States affiliated Pacific Island Jurisdiction standing united to speak in one voice around the shared issues of HIV/AIDS in our island communities.

- We advocate for the provision of quality HIV prevention and care services in the region.
- We advise national, international, and local policy entities on HIV/AIDS
- We strengthen and coordinate AIDS activities through the sharing of information and resources within the region

PIJAAG strongly advocates for changes in the response to the AIDS epidemic in the Pacific region, both internally as a region and externally from federal agencies like the Centers of Disease Control & Prevention (CDC) and Health Resources and Services Administration (HRSA). PIJAAG sees the need to develop a regional model of HIV prevention and services.

PIJAAG feels strongly that twenty years into the epidemic with no relief in sight, several changes need to be made to respond to the AIDS epidemic in the Pacific region.

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## THANK YOU !

*PIJAAG would like to thank and extend its sincere appreciation to the following partners, agencies, and individuals for making this Summit a success:*

American Samoa Department of Health  
Commonwealth of Northern Marianas Islands  
Department of Public Health  
Federated States of Micronesia Department of Health  
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Guam Department of Public Health and Social Services  
Republic of the Marshall Islands Ministry of Health  
Republic of Palau Ministry of Health  
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Asian and Pacific Islander Wellness Center  
Hawai'i Multicultural HIV Resource Project  
Maui AIDS Foundation  
Centers for Disease Control and Prevention  
Human Resources and Services Administration

Republic of Palau Government  
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Virginia Bourassa - Washington, DC





# Notes

# Caring for Persons Living With HIV/AIDS On Guam

## *Needs Assessment Report* and Guam HIV/AIDS Care Plan

### PREPARED FOR:

The Guam HIV/AIDS Prevention Community Planning Group;  
Ryan White CARE Act Needs Assessment Advisory Council; and the  
Office of Planning and Evaluation, Department of Public Health and Social Services

**May 2003**

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**DISCLAIMER:**

The views and interpretations contained within this report are those of the authors and do not necessarily reflect the policies or views of the University of Guam, the Department of Health and Social Services, or the Human Resource Services Administration.

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*The programs of the University of Guam Cooperative Extension are open to all regardless of race, age, color, national origin, religion, sex, or disability.*



## DEDICATION

It was through the efforts of many people that this Needs Assessment Study and Guam Plan for Persons Living with HIV/AIDS was possible. A special thanks to the HIV infected and affected community for their insight and commitment to improving HIV care services on Guam. Guam lost several during this project. One who was deeply involved with this project was a family care giver, who is remembered here by his family.

### Joseph F. P. Cruz ( July 7, 1958-Dec. 02, 2002)

Joseph F.P Cruz was a very spiritual, loving, caring, patient, understanding, and most of all a supportive man. When he heard about the disease that I have he loved me even more. Instead of pushing away, he pulled closer. He wanted to help me in this project, but the Lord took him before he could finish. He would always think of ways to help. He would always participate in workshops with me and he loved that he was helping and being a part of this worthwhile project. It was funny because he was legally blind and I have meningitis, so I was his eyes and he was my memory... we were one. He was the kind of man that rarely got mad. If you needed a laugh all you had to do was look for Joe, he always brought a smile to people's faces. Despite his disability he always gave 110%. He will always be in our hearts, thoughts, and prayers. We love you. Angel, Liz, Matthew and Venecia

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Also thank you to the many people who were alternates for Needs Assessment planning members, and to the many interested individuals in the community who participated in Consortia meetings at various times.

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Caring for Persons Living With  
HIV/AIDS On Guam  
***Needs Assessment Report***  
and Guam HIV/AIDS  
**CARE PLAN**



Submitted by:

**Economic & Community Systems  
Guam Cooperative Extension  
University of Guam  
and the  
Coral Life Foundation**



## Executive Summary

This needs assessment study for Persons Living With HIV/AIDS (PLWHA) on Guam used both existing data from community agencies and health surveillance surveys (see Epi Profile Report pages 11 to 16), and a multi-method research design to collect data from key informants of PLWHA, their family care givers, and service providers on Guam (see Needs Assessment Research Methodology pages 17 to 19).

Through a participatory research and planning process, these data facts were used by the community Advisory Group and their associates to identify nine (9) service needs and service gaps (see pages 71 to 82). The community then developed a shared list of values and a vision for a system of care services that they want to see developed to meet the needs of PLWHA on Guam (see pages 7 to 9). With these values and vision in mind, the community then developed specific identification of service resources for each of the nine needs, a listing of challenges and barriers for those needs, and finally a set of recommended actions to overcome the barriers. (see Guam HIV/AIDS Care Plan, pages 83 to 113).

Selected priority recommended actions of the Guam HIV/AIDS Care Plan, are:

Continued community HIV/AIDS care planning and consumer involvement must be formally organized and structured in a way that this function is sustainable and effective even in times of economic hardship limiting local funding sources, and without over dependency on federal funding which also cannot be guaranteed over the coming decade.

The existing Guam CPG will establish an intermediate HIV/AIDS planning body as a subcommittee and working task force for implementing the Guam HIV/AIDS Care Plan in this report document to formally organize Guam's continued care planning entity and process over the next year 2003-2004.

At the Department of Public Health & Social Services, the Bureau of Communicable Disease Control, will work with the Office of Planning and Evaluation, to get technical assistance from HRSA and CDC to define program data requirements, and the data collection and reporting methodologies which can obtain useful and timely information for planning and programmatic purposes.

The DPHSS Bureau of Communicable Disease Control's STD/HIV Program, and Medical Social Service Unit should network with the Guam Medical Society, and other professional societies (i.e., nurses, dentists and pharmacists) to develop case management protocols to increase the number of persons testing HIV positive who receive follow-up counseling with continuing coordinated care.

The Guam HIV Prevention CPG subcommittee group should contact the US Office Minority Health Resource HIV Education and Training Center, in San Francisco, CA, to request training and technical assistance to help them advocate for these recommended actions.

The Guam HIV Prevention CPG subcommittee group, GMHA Education, and UOG PEACESAT should work with regional associations like PIJAAG, Pacific Island Health Officers Association, (PIHOA) to adapt the training needs identified in the various sections of this plan into formal regional requests to HAETC/PAETC for training and telemedicine conferences. The aim is to increase the number of Guam and regional physicians and health care providers benefiting from AETC educational and consultation services.

Local non-government, community-based organizations, like Dream For a Cure, Coral Life Foundation (CLF) and GUAHAN Project (Guam HIV AIDS Network), and DPHSS ADAP program, should educate PLWHA and care givers on their individual rights for confidentiality and privacy issues.

Local non-government, community-based organizations, like Coral Life Foundation (CLF) and GUAHAN Project (Guam AIDS HIV AIDS Network), and DPHSS ADAP program, should network with national organizations such as HRSA, the Asian & Pacific Islander Wellness Center, and the pharmaceutical compassionate programs to:

- increase the capacity of PLWHA to purchase medications on-line and off-island at discount rates.
- negotiate for the best drug-pricing for anti-retroviral drugs to benefit all PLWHA, the insured, under-insured and un-insured (i.e., a One-Stop).

DPHSS should pursue Early Intervention Services (EIS) program funding, and Ryan White Title II & Title III funding. GHURA should pursue discretionary funding under Housing Opportunities for People With AIDS (HOPWA). HIV/AIDS community-based organizations such as the GUAHAN Project should apply for grant money to be able to also become part of the community network of services that can be coordinated and linked in some kind of a case management system.

The AIDS Education and Training Center (AETC) could be utilized to facilitate this training on Guam and in the region.

Link up with Guam's Washington delegate in Congress to advocate for Guam's System of Care Services

Revamp eligibility requirements to be more inclusive of HIV/AIDS. This may require a restructuring of insurance coverage.

Community-based organizations need to provide psychosocial support for PLWHA. Free or low-cost counseling services that do not require insurance coverage are needed for PLWHA. Public awareness community events for HIV/AIDS education must take place.

Funding streams must be identified to support peripheral issues such as childcare, estate planning, survivor benefits, and so forth. These are important to clients and a system of addressing these needs must be developed as part of the System of Care Services.

Representatives from the Department of Revenue and Tax, which regulates Guam's health insurance industry, and MIP at DPHSS must be included on any AIDS advisory consortia, or Governor's Inter-agency AIDS Task Force.

Local AIDS NGOs should obtain national technical assistance to conduct training for island leaders on current standards of drug coverage by insurance plans, and how Guam should update defined formularies provided in island insurance plans to assure coverage of newly emerging medications.



## Introduction

Guam has had an active HIV Prevention Community Planning Group (CPG) since 1994. Over the years this group discussed issues concerning the needs of persons living with HIV/AIDS (PLWHA), yet the group's function is to address HIV education and prevention programs. The needs and organized development of services for PLWHA were not receiving sufficient attention. CPG members, service providers and PLWHA on-island have advocated for years that something must be done. This advocacy intensified along with the ever increasing number of persons testing HIV positive and being diagnosed with AIDS on Guam and in the surrounding island region (see Epi Profile Tables 2.1 and 2.2).

In many communities of the United States, prevention planning and care planning are conducted separately because the two are funded by different and separate parts of the Department of Health and Human Services. HIV/AIDS Care Planning is via Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Title I and Title II funded by the Health Resources and Services Administration. Prevention Planning is done by Federally mandated Community Planning Group process funded via the Centers For Disease Control.

There are an increasing number of communities who are combining these two planning functions to create a continuum of HIV/AIDS services that extends from prevention programs, to testing and counseling, to early intervention treatment and access to care services for PLWHA. This project was designed to be a combined needs assessment study and a planning process to address services targeting Guam's community network of PLWHA, their family and support networks, and both public and private sector health care service providers.

The project was conducted as a Participatory Research Process, which, as a strategic approach, places emphasis on "ownership" of any project by the people being investigated. The project was guided by the project's Ryan White Needs Assessment Study Council, organized for this very purpose. Participatory Research methods seek to develop mutually beneficial cooperation among individuals and groups, and stress the use of dialogue as an essential procedure for the creation of useful knowledge, and its application in the development of plans.

There are factors that effect any type of data collection about HIV/AIDS on Guam. These same factors also have an impact on community mobilization for HIV/AIDS, lobbying efforts, service planning, funding and networking. This project encountered a number of these factors, and Coral Life Foundation (CLF) staff members and volunteers learned a lot as they met and talked with the Guam community in search of PLWHA to participate in the project. Their experiences, and the knowledge they gained about working with PLWHA on Guam, are findings produced by this needs assessment that are as important as those that came from the survey and focus group research methodologies which were used. The project had not considered the use of an ethnographic, participant observation research methodology. Yet, as this report was being written the authors realized that this research methodology had in fact occurred as the depth of the knowledge gained by CLF staff and volunteers was written up. The following section presents these ethnographic findings.

### **The Involvement of Persons Living with HIV/AIDS in Need Assessment Studies and Care Planning Events: Ethnographic Insights**

The size of the community (approximately 153,000 people) and the very close interpersonal lifestyle of people were major factors that influenced efforts to get persons living with HIV/AIDS (PLWHA) on Guam involved in the HIV/AIDS needs study and care service planning events. The geographic

isolation of the island of Guam from major urban centers in Asia, Hawaii and the world make the community feel even smaller in perception and in fact. Many people inevitably find out life details of other people regardless of assurances of confidentiality and efforts to maintain discretion.

In the Guam HIV Prevention Community Planning Group (CPG) and the AIDS Advisory Group, there were PLWHA members and individuals with family affected by this disease. These individuals were sources of information with great material benefit to data collection and planning. Yet, there were PLWHA and family caregivers who choose not to be involved.

This project was also helped by PLWHA with ties to Guam's health care industry and the University of Guam (i.e., family or themselves). But there were also health care providers, students and faculty living with HIV/AIDS who were not comfortable participating in events, because their colleagues and associates were often present. These factors of a small community limited participation of some PLWHA and some service providers who are themselves PLWHA.

There were other examples of PLWHA who conscientiously made the choice not to get involved in this work. Some cited fear of discrimination and deportation. There are PLWHA who are not U.S. citizens who fear they may be deported from Guam. Such efforts by Pacific Island governments have occurred in the region and there are people in the community who speak of the idea. Others fear losing health insurance, not only for themselves but also for their families. There are also a number of PLWHA who have substance abuse issues. For many of these people, their substance abuse is one of several co-factors limiting their effectiveness as survey participants or as active members in such entities as the AIDS Advisory Group and the Guam HIV Prevention CPG. Separate from illegal drug use, there were some who feared being caught receiving services obtained under false information or misleading statements. As a consequence, these individuals are guarded with details of their lives.

In some cases, people feared disclosure of their sexuality or their extramarital affairs that may involve same-gender sexual relationships. These include people with families and grown children. There are some PLWHA within the Guam community that hold key leadership and public trust positions. These individuals expressed concern that they may lose support and the ability to serve the community if their HIV status is known publicly. They also are concerned about the ridicule and isolation that living with HIV/AIDS often brings.

Another factor effecting data collection and planning is local perceptions that public self-disclosure of one's HIV positive status does not necessarily rally community support. There are cases of PLWHA who have made their status known to the Guam community. For over ten years, such calls for mobilization and a redefinition of health care services for PLWHA have been made by several courageous individuals. Unfortunately, this has not significantly changed the views of professional associates and colleagues and has not led to any major changes of HIV/AIDS health care on Guam.

Finally, there were some PLWHA who declined participation because they think that services on Guam cannot be improved, or that it's inconsequential to their lives. Some of these individuals accessed all care from off-island care providers. Others had the resources to have personal professional nursing and doctor care paid out-of-pocket. Still others were non-symptomatic and preferred not to participate in the project in any way.

These factors were encountered during this needs assessment study and planning project. There were, however, many other clients who were willing to work closely with the University of Guam and Coral Life Foundation. Their invaluable life experiences and wealth of shared information gave this project direction and grounding to help establish an effective case management system of care services to PLWHA on Guam.



## Overview of Project and Process

This project conducted a participatory research and planning process involving the community from beginning to end. Unfortunately, over the course of the project three major typhoons hit Guam and disrupted the process. This delayed the project, and required modifying some of the specific events, but the overall goal was eventually achieved. The purpose of this document is to provide Guam's community with evidence-based information for decision-making and action by individuals engaged in developing services for *Persons Living With HIV/AIDS* (PLWHA).

The Guam HIV/AIDS Consortia Conference, held April 26, 2002 was a collaborative effort between public agencies and community non-profit organizations supported by two grant-funding sources<sup>1</sup>, with in-kind resource help from a larger network of programs and volunteers. The "First" conference began organizing communications and links within Guam's network(s) of service providers, caregivers, and consumer clients so the community could address the needs of PLWHA. The longer-range goal was to conduct a needs assessment study producing useful information, which could be applied in the development of an HIV/AIDS care plan. For this purpose, participants from the first consortia were solicited to organize a working advisory group (see Appendix A).

The *Guam Ryan White CARE Act Needs Assessment Advisory Council* was formed to involve the community in the needs assessment and eventual application of information for planning. The Advisory Council came to be composed of 37 members of the community, including PLWHA and care givers, community-based organizations, physicians caring for PLWHA, and individuals from public agencies and the Department of Public Health and Social Services with experience serving PLWHA. The first Advisory Council meeting was held June 26, 2002. The primary tasks in this time period from May through June were to design the needs assessment study, prepare its data collection instruments for the service providers and the PLWHA's, and decide on protocols for data collection. Members contributed greatly to these decisions. A second Advisory Council meeting was held June 31, 2002 just as data collection was started. The process was disrupted by two typhoons that struck Guam the first and second week of July. Data collection resumed from August through September into October 2002. Preliminary data from the surveys were presented at the Advisory Council's fifth meeting held October 31, 2002. The Advisory Council assisted in the design and helped conduct a series of three focus groups held during November 2002. This was the final data collection effort of the needs assessment study. The focus groups were tape-recorded and transcriptions of this qualitative information were processed and analyzed during November and December 2002.

The Second Guam HIV/AIDS Consortia held December 6, 2002, presented preliminary findings of the needs assessment study to the community. This was conducted to specify the "needs" identified by the evidence collected, and initiate consortia meetings to develop recommendations for a Guam HIV/AIDS care plan to address the identified needs. Once again, just as this stage of the project started, a super-typhoon struck Guam December 8, 2002. The project did not get back to the work effort until the end of January 2003. The Advisory Council held two more meetings (1/29 and 2/7 / 2003) where they developed a plan to conduct working sessions and develop recommendations for a Guam HIV/AIDS care plan. Six sessions were held through the months of February and March.

Following an established and formal strategic planning process, the first elements developed for Guam's HIV/AIDS Care Plan were listings of the community's ethical values to guide services for PLWHA, and its underlying beliefs and assumptions supporting these values. These were drafted by

<sup>1</sup> Funded in part by a Mini-Planning Grant from the Association of Asian Pacific Community Health Organizations (AAPCHO) to Guam DPHSS, and by sub-contract of Ryan White Title III funding from IIRSA, US Department of Health and Human Services via Guam DPHSS to the University of Guam.

the Guam PLWHA and care service providers attending the first of the six planning sessions (February 14, 2003). The clarification of these values and beliefs helped the working group develop a vision statement to guide decision makers on the kind of system of care for PLWHA that this Guam Plan aims to create by actions over the next several years. Specifying a vision statement has been established as a critical element for developing a strategic plan. It is often the most permanent element, lasting longer than specific individual recommended actions, which must be revised and up-dated if they do not actually occur during the 1 to 2 year time period after the plan has been written. For these reasons, the vision statement developed by the PLWHA, caregivers, and participating HIV/AIDS service providers has been placed at the beginning of this report document.

The remainder of this document begins with a presentation of the community's values and vision for developing care services for PLWHA on Guam. The report then follows with a presentation of the HIV/AIDS epidemiologic data profile prepared by the Department of Public Health and Social Services, and then follows with the more in-depth needs assessment study conducted to help develop the Guam HIV/AIDS Care Plan. The next several sections present a description of the methodologies used and the data evidence on persons testing for and living with HIV/AIDS on Guam. These findings are followed by a summary of the needs identified by the Advisory Council's review of the data and evidence. The Guam HIV/AIDS Care Plan is then presented. For each of these needs, working task groups of the Advisory Council identified (1) resources available to implement actions, (2) service challenges and barriers needing action, and (3) recommended actions to overcome service challenges or barriers that will improve the level of care provided to PLWHA on Guam.



## **Mission Statement of a Guam System of Care Services For People Living With HIV/AIDS (PLWHA)**

- To bridge together PLWHA, families and the community with established services so that everyone is knowledgeable of HIV/AIDS and that a system of care services on Guam is funded and supported by the community.
- To continually evaluate, improve and support services that cover the full range of needs from testing and early HIV stages to late AIDS stages and support for families and children after death.
- To bring together health and social service providers so Guam's system of care services for PLWHA can develop all services that are needed, and ensure that services are compassionate and the consumer is treated with dignity.

### **Values**

(Guiding Principles agreed upon by PLWHA and Service Providers)

- Community support for People Living with HIV/AIDS must be non-judgmental.
- Knowledgeable expertise and professional specialization in HIV/AIDS treatment is essential, and that Guam has at least one or more medical specialists.
- Services are compassionate and the consumer is treated with dignity.
- The full-range of needs extends from testing and early HIV stages to late AIDS stage and continue after death.

### **Underlying Assumptions**

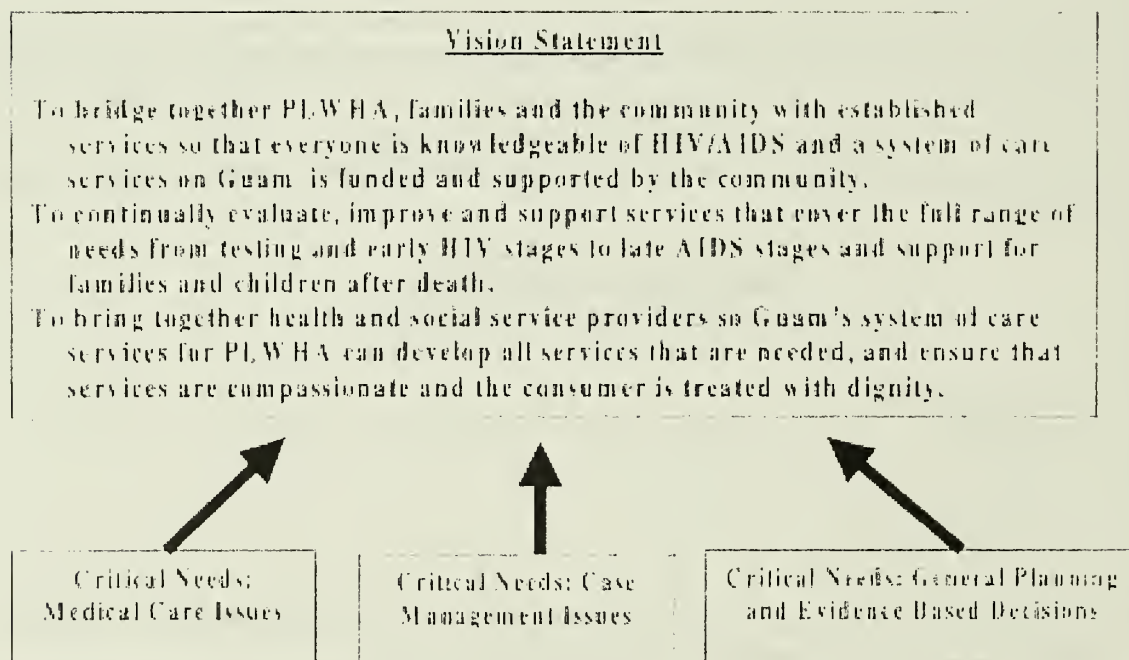
(Combined PLWHA and Service Providers)

- Case management must be:
  - a.) effective
  - b.) fair
  - c.) compassionate
  - d.) professional
- Case management must operate with the understanding that some of the consumers' underlying problems may not stem from their HIV/AIDS diagnosis.
  - a.) Although services may be available, however, there may be serious access barriers.
  - b.) Medications must be accessible, that is, be dispensed properly and must work.
- Just because services exist, they may not be effective, efficient or they may not be all of the services that are needed.
- The community needs to be unified and services need to be linked and coordinated. The community needs to support PLWHA. The stigma and bias associated with HIV/AIDS must end.

## Developing a Comprehensive Guam AIDS CARE Plan

What do we want to happen? We want our values made real and manifest in the world.

<u>Values:</u>	<u>Underlying Assumptions:</u>
Community support for People Living with HIV/AIDS (PLWHA) must be non-judgmental	Case management must be effective, fair, compassionate, and professional
Knowledgeable expertise and professional specialization in HIV/AIDS treatment is essential, and that Guam has at least one or more medical specialists	Case management must understand that some of the community's underlying problems may not stem from their HIV/AIDS diagnosis
Services are compassionate and the consumer is treated with dignity	Although services may be available, however, there may be serious access barriers
The full-range of needs extends from testing and early HIV stages to late AIDS stage and continue after death.	Medications must be accessible, that is, be dispensed properly and must work
	Just because services exist, they may not be effective, efficient or they may not be all of the services that are needed
	The community needs to be unified and services linked and coordinated – the community needs to support PLWHA to end the stigma and bias associated with HIV/AIDS



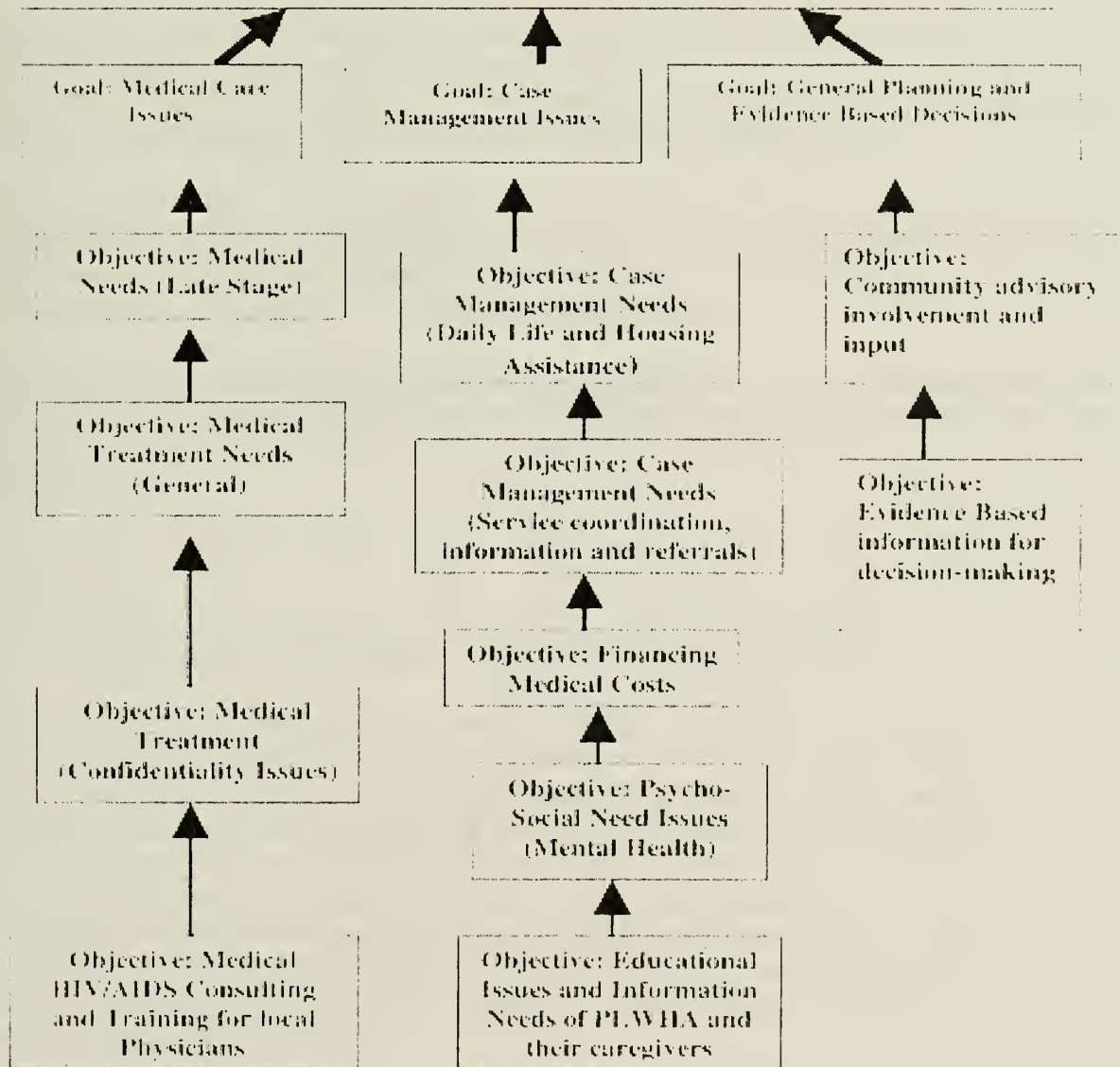
How do we get  
FROM WHERE WE ARE NOW TO WHERE OUR VISION IS ACHIEVED?

### Vision Statement

To bridge together PLWHA, families and the community with established services so that everyone is knowledgeable of HIV/AIDS and that a system of care services on Ginnu is funded and supported by the community.

To continually evaluate, improve and support services that cover the full range of needs from testing and early HIV stages to late AIDS stages and support for families and children after death.

To bring together health and social service providers so Ginnu's system of care services for PLWHA can develop all services that are needed, and ensure that services are compassionate and the consumer is treated with dignity.







## Epidemiological Profile Report

Prepared for the Guam HIV Prevention Community Planning Group

### I. EXECUTIVE SUMMARY

New cases of HIV infection reported annually on Guam reached an all-time high of 15 in 1996. The trend with regard to AIDS cases is less clear but may have reached a peak in 1994. **Residing in the U.S. mainland, or travel to it, continues to be the most common source of HIV infections diagnosed on Guam.**

**Male-male sex is the most frequent risk behavior associated with new cases of HIV** on Guam; **heterosexual acts are the second** most common HIV case-associated risk category for males but is the most common risk factor for female cases. **The incidence of AIDS (both sexes) is greatest among those 30-39 years of age and, in this age group, it is highest among Chamorros.**

Guam's incidence of HIV infection in recent years (1995-1998) has been greatest among Blacks, all residing in Guam's Northern region. The incidence among all other ethnic groups has been highest in the Central Region. Male-male sex has been associated with more HIV cases than any other risk factor and persons in this risk group with HIV tend to live in the Central Region.

In 2000 there was a **60% drop in the number of reported HIV** positive cases! The average number of new cases for the 5-year period 1995 to 1999 is 12.6; in 2000 Guam only had 7 HIV cases reported. This is a major change. The chart below displays these indicators, and the trend continued in 2002 (see Charts D1 and D2).

	1993	1994	1995	1996	1997	1998	1999	2000
Number of cases	10	9	12	15	10	15	11	5
Incidence Rate	6.96	6.3	8.34	10.35	6.83	10.06	7.25	4.52

### II. THE IMPACT OF HIV/AIDS ON THE POPULATION OF GUAM

The number of new HIV cases reported on Guam each year was erratically low in the first years of testing for the disease 1985-89 (see Table 2.1). The average number of annual new cases across these 5-years was only (mean) 2.8 cases. Then **new cases dramatically jumped to a higher level in 1990. The numbers and rates remained at this new level for the entire decade**, with only slight fluctuation up/down. Following 1991, the number declined for 3 consecutive years (Table 2.1). In 1995, 1996 and 1998, however, cases of HIV increased once again; the average for the first 5 years of the decade was only slightly lower than the average for the second half of the decade (Mean 1990-94 = 10.1 versus Mean 1995-99 = 12.5). Because of the relatively small numbers involved, however, interpretations of the significance of these data must be viewed with some caution. Yet, scanning across the fifteen years 1985-99 the pattern is of a step-up every 5 years:

Time Period	<u>1985-89</u>	<u>1990-94</u>	<u>1995-99</u>
Mean New Cases	2.8	10.1	12.5

**Table 2.1      Number of HIV infections, AIDS cases, and incidence rates by year, Guam, 1985-2000.**

YEAR	HIV CASES (Rate <sup>1</sup> )	AIDS CASES (Rate <sup>1</sup> )
1985	1 (0.84)	0 (0.00)
1986	4 (3.27)	2 (1.64)
1987	1 (0.80)	1 (0.80)
1988	7 (5.48)	1 (0.78)
1989	1 (0.77)	1 (0.77)
1990	12 (9.70)	2 (1.49)
1991	13 (9.54)	4 (2.91)
1992	11 (7.81)	2 (1.42)
1993	10 (6.92)	5 (3.46)
1994	9 (6.07)	11 (7.42)
1995	12 (8.28)	2 (1.31)
1996	15 (10.35)	10 (5.79)
1997	10 (6.83)	5 (3.41)
1998	15 (10.06)	7 (4.69)
1999	11 (7.23)	8 (5.26)
2000	7 (4.52)	2 (1.29)

<sup>1</sup> Cases per 100,000 population.

Seven of the 10 new AIDS cases in 1996 were reported concurrently with their first HIV positive report, suggesting that transmission of HIV may have occurred years earlier. Additionally, none of the 10 1996 AIDS cases are known to have contracted their infections on Guam. This apparent sudden increase in the incidence of AIDS may reflect conditions with regard to HIV transmission years earlier in the U.S. rather than on Guam (Table 2.2). In 1996 the number of HIV infections first diagnosed on Guam but apparently contracted in U.S. mainland surpassed a previous all time high of 7. Data in 1998 reflects an increase in the number of indigenous cases of acquired HIV infection.

**Table 2.2      Cases of HIV infection initially reported on Guam and the areas in which they were apparently contracted, 1985-2000**

Year	Source Area.				Total
	Guam	USA	Africa	Unknown	
1985	1	0	0	0	1
1986	0	4	0	0	4
1987	0	1	0	0	1
1988	5	1	0	1	7
1989	0	1	0	0	1
1990	5	3	0	4	12
1991	4	5	0	4	13
1992	1	3	0	7	11
1993	3	7	0	0	10
1994	3	4	0	2	9
1995	5	6	1	0	12
1996	3	9	0	3	15
1997	4	4	0	2	10
1998	9	4	0	2	15
1999	4	6	0	1	11
2000	5	1	0	1	7
Total	52	59	1	27	139

The Centers for Disease Control case definition of AIDS for surveillance of AIDS was expanded in 1993 to include additional indicator conditions and, as a result, some cases of AIDS were counted that year that would otherwise have been included in subsequent year's totals. This procedural change had a substantial impact on AIDS reporting trends in the U.S. that year but apparently had less impact on Guam (Figure 2.1). Since then, the incidence of AIDS has gradually decreased in the U.S. While the incidence of AIDS on Guam is still low compared to California, Hawaii, or the U.S. as a whole, it does not appear to be decreasing significantly and may be increasing among some ethnic groups. Although it is not possible to draw firm conclusions in this regard because of the very small numbers involved, this situation will continue to merit close monitoring in the future.

Although the incidence of AIDS on Guam has been much less than that of the U.S., it is higher than that of many of our island neighbor countries (Table 2.3). The differences observed, if real, may be more the result of differences in geographical isolation and population mobility rather than differences in sexual practices or control program activity. Differences in the availability of diagnostic services and the efficacy of disease reporting schemes may also play a part in the observed differences. The apparently low rate reported for Singapore is surprising in view of the cosmopolitan nature of that community and their advanced economic status.

**Table 2.3 Cumulative incidence of AIDS in Guam and other areas of regional interest 1985-2000<sup>3</sup>**

Area	Total cases	Cumulative Incidence Rate <sup>1</sup>
Guam <sup>2</sup>	64	41.34
Samoa <sup>3</sup>	6	
Japan <sup>3</sup>	2,006	
Palau <sup>3</sup>	2	
Marshall Islands <sup>3</sup>	2	
Australia <sup>3</sup>	8,354	
China <sup>3</sup>	707	
French Polynesia <sup>3</sup>	74	
S.Korea <sup>3</sup>	186	
Northern Marianas <sup>3</sup>	14	
Malaysia <sup>3</sup>	4,118	
FAS Micronesia <sup>3</sup>	3	
New Caledonia <sup>3</sup>	77	
New Zealand <sup>3</sup>	736	
Philippines <sup>3</sup>	470	
Singapore <sup>3</sup>	698	
Tonga <sup>3</sup>	8	
Vietnam <sup>3</sup>	3,877	
Global <sup>3</sup>	36.1 million	

<sup>1</sup> Total reported cases per 100,000 of current population (most recent census data available).

<sup>2</sup> Guam Dept. PH&SS, 2000.

<sup>3</sup> WHO STI/HIV/AIDS Surveillance Report, October 2000<sup>1</sup> Total reported cases per 100,000 of current population (most recent census data available).

<sup>2</sup> Guam Dept. PH&SS, 2000.

<sup>3</sup> WHO STI/HIV/AIDS Surveillance Report, October 2000

No cases of HIV infection in females were reported on Guam before 1990 but since then an average of 2 female cases have been reported each year. The age group with the highest incidence of HIV infection among females during 1990-94 and 1995-1999 was 20-24. During the period 1985-1989 males 25-29 had the highest HIV incidence rate for their gender while more recently the age group 30-39 had the highest attack rate (Table 2.4).

**Table 2.4 Average annual HIV incidence by age group and sex for 5-year periods, Guam, 1985-1999.**

Age Group	1985-1989		1990-1994		1995-1999	
	Male(Rate <sup>1</sup> )	Female(Rate)	Male(Rate)	Female(Rate)	Male(Rate)	Female(Rate)
0-14	0(0.0)	0(0.0)	0(0.0)	0(0.0)	1(0.4)	0(0.0)
15-19	0(0.0)	0(0.0)	1(1.7)	1(1.8)	1(1.8)	0(0.0)
20-24	2(2.6)	0(0.0)	9(11.6)	5(8.5)	1(1.8)	3(5.9)
25-29	6(9.0)	0(0.0)	5(6.3)	2(3.2)	6(9.7)	0(0.0)
30-39	7(6.5)	0(0.0)	18(14.3)	1(1.8)	32(24.8)	4(3.7)
40-49	0(0.0)	0(0.0)	8(9.4)	1(1.8)	7(6.8)	4(3.7)
50-59	0(0.0)	0(0.0)	1(1.7)	0(0.0)	2(3.4)	0(0.0)
60+	2(2.6)	0(0.0)	0(0.0)	0(0.0)	2(3.4)	0(0.0)
Total	17(2.5)	0(0.0)	42(5.5)	10(1.5)	52(6.6)	11(1.5)

<sup>1</sup> Cases per 10,000 population

When the incidence of HIV infections on Guam is examined over time by the ethnicity of affected persons, it is clear that the general trend of increased incidence of HIV has impacted most ethnic groups (Table 2.5).

**Table 2.5 Summary: HIV incidence<sup>1</sup> by ethnicity, Guam, 1985-1999.**

Ethnicity	1985-89	1990-94	1995-99
Chamorro	16.5	38.4	41.9
Filipino	15.2	3.7	14.0
F.S.M.	0.0	51.8	120.6
Marshall's	0.0	0.0	151.5
Palau	0.0	0.0	0.0
Asian	0.0	18.7	0.0
Caucasian	13.9	82.7	85.1
Black	34.9	67.0	246.0
Other	0.0	40.2	67.3
TOTAL	13.6	36.6	43.2

<sup>1</sup> Annual Cases per 100,000 population



Both “years of life lost due to HIV/AIDS” and “age-adjusted death rates due to HIV/AIDS” data (Tables 2.6 and 2.7) suggest that the impact of HIV/AIDS on the Guam community has increased substantially even though it remains significantly less than in the continental U.S.

**Table 2.6 Years of potential life lost due to HIV/AIDS per 100,000 population under 75 years of age, USA and Guam<sup>1</sup>.**

Area	1995	1996	1997	1998	1999	2000
Guam	207.5	81.0	142.0	51.0	0	32.4
U.S.A	615.0		435.1	N/A	N/A	N/A N/A

<sup>1</sup> Prepared by the Office of Territorial Epidemiologist, GDPHSS.  
N/A – Not Available

**Table 2.7 Age-adjusted death rates from HIV/AIDS, Guam.<sup>1</sup>**

Area	1985-89	1990-94	1995-99
Guam	1.1	2.7	2.26

Note: USA age-adjusted rate for 1997 was 5.8 per 100,000 population

<sup>1</sup> Prepared by the Office of Planning and Evaluation, GDPHSS.

Survival following infection with HIV may be influenced by a number of factors, including general health of the patient, efficacy of the medical treatment available, how early in the illness medical treatment is begun and possibly psychological factors as well. Unfortunately in many cases the presence of HIV infection is not recognized until AIDS is present or until the patient has expired (“years survived” equal to “0”). In such cases years of life may be unnecessarily lost because the patient has not been under appropriate medical treatment. Specifically with regard to Guam (Table 2.8), transfusion-associated cases show a low “mean days survived” figure, probably because these cases occurred at a stage of the pandemic when AIDS awareness was at a relatively low level even among medical personnel and these infections were not recognized until far advanced.

Among other risk categories of Guam patients that have died as a result of HIV infection, heterosexuals have the lowest “mean days survived” value suggesting that identification of their HIV-positive status was late in their illness and that additional effort could be expended towards early identification of cases among persons in this risk category.

**Table 2.8: Mean number of days until death following report of HIV positive status by risk category, Guam, 1985-2000.**

Risk category	Cases	Mean days survived
Bisexual	5	433
Transfusion	2	106
Hemophilia	1	804
Heterosexual	4	151
Male-male sex	17	639
Male-male sex/IVDU	2	493
IV drug use	1	161
Unknown	5	0
Total	37	475

**Summary** - New cases of HIV infection reported annually on Guam peaked at 13 in 1990 and then decreased slightly through 1994. Years 1995, 1996 and 1998, however, saw subsequent increases to an all-time high of 15 cases. Male-male sex is the risk category associated with the most new cases of HIV on Guam, heterosexual sex is the second most common HIV case-associated risk category. The incidence of HIV is currently greatest in the 30-39 year age group. No females were diagnosed with HIV on Guam before 1990; through 1994 heterosexual sexual activity accounted for all female HIV cases save one which was due to IV drug use.

## Needs Assessment Research Methodology

This project conducted a multi-method assessment study on the needs of persons living with HIV/AIDS (PLWHA) on Guam. The study and the Advisory Council's planning meetings utilized assembled data from the annual epidemiologic profile prepared for the HIV Prevention Community Planning Group of the Department of Public Health and Social Services. The needs assessment also collected both quantitative and qualitative information from three targeted groups of persons:

- (1) Medical, health and social service providers to Persons Living With HIV/AIDS (PLWHA).
- (2) Persons Living With HIV/AIDS (an availability sample obtained from contacts made through service providers).
- (3) And persons who had experience as care-givers for PLWHA (i.e., partner, relative, or friend).

Data collection followed guidelines and examples by the Human Resource Services Administration, Department of Health and Human Services. Survey questionnaires were developed and quantitative data collected from (1) service providers to make contact with PLWHA, and, in turn data was collected from (2) PLWHA. A focus group methodology was also employed to collect qualitative information from all three targeted populations (1-3).

### Data collection instruments and protocols:

1. **Survey of Service Providers.** A listing of known providers of services to PLWHAs was expanded through network communications inviting service provider professionals to an HIV/AIDS consortia conference (held April 26, 2002). This listing of service providers was supplemented with input from the project's Advisory Council and arrangements to distribute this survey out through the membership network of the Guam Medical Society. In addition to obtaining a count of PLWHA receiving services, the aim of this survey was to identify medical and social service programs who could contact PLWHA and solicit their participation in this needs assessment study (see Appendix B).
2. **Survey of PLWHAs.** PLWHA were contacted and provided questionnaires (see Appendix C) by their service providers. This maintained a trusted relationship and protected the confidentiality of personal information. Service providers who had PLWHAs as consumer clients (including institutionalized persons) were asked to solicit informed consent from their consumer clients. Confidentiality was maintained such that our response rate and returned surveys were limited to persons willing to consider participation, and even then subjects could choose to remain completely anonymous to the project (see procedures for "Confidentiality" on page 18).



## **Data Collection Procedures and response rate:**

Record log sheets were given to service providers to track the surveys distributed and returned. For PLWHAs who were minors, the parent/guardian was solicited and asked to complete the survey instrument. The parent could involve the minor if they were of sufficient age to be able to complete the survey on their own (i.e., infant PLWHAs versus teenagers).

Confidentiality and maintenance of anonymity was assured, and arrangements for conducting interviews with those PLWHAs who agreed to respond by choosing one of two options as selected by the consenting PLWHA.

Trained interviewers (HIV/AIDS Outreach Workers from CLF) conduct the survey with consenting PLWHA or parent/guardians at a site the consumer selects, and provided them with a gift incentive (\$25 value) upon completion of the questionnaire. This was the project's preferred option to optimize accuracy and completeness of collected information, some of which is technical, but also because of the complexity of the survey instrument itself.

**NOTE:** Interviewers were trained to monitor the possibility of stress or emotional reaction to question content. The project had had this very reaction by a PLWHA who presented at the first consortia conference. Interviewers (HIV/AIDS Outreach Workers from the Coral Life Foundation) were trained by Henry O'Campo, Asian Pacific Islander Wellness Center of San Francisco, CA, as part of his technical assistance project working with Guam's Coral Life Foundation. For those who anonymously completed the survey, instructions specified they could choose not to answer, or completely stop at any point. In the focus group methodology, the PI and trained staff were in attendance to counsel individuals at the session.

PLWHA were offered to maintain complete anonymity and contribute to the project by choosing to self-administer the questionnaire and return the survey via their service provider, or through a stamped, pre-addressed envelope provided by the needs assessment project.

The study attempted to contact as many PLWHA on-island as possible. The primary source of contact was via service providers to their consumer-clients. Physicians who had responded (see table 1) reported having 48 PLWHA patients receiving medical care, and service programs reported having 60 PLWHA as consumer-clients. The extent of duplication could not be determined. Assuming the physicians provided an unduplicated count it is estimated the study contacted about 55 PLWHA in this way (i.e., between 48 up to 60). The Coral Life Foundation outreach staff and volunteers put out announcements and talked with key informants (their PLWHA clients and Gay Men's Support Group) to contact PLWHAs residing on island but not receiving services (see Introduction: Ethnographic Insights). These efforts reached an additional eleven (11) PLWHA. With 28 returned surveys the response rate is estimated to be between 43% and 50 percent of PLWHA contacts in the community.

## **Need assessment data set and availability for secondary analyses:**

Interview responses were marked directly in the questionnaire booklets, which were mailed in or delivered by the interviewers to the University of Guam, to be entered into a machine readable data file using the SPSS (Statistical Package for the Social Sciences) software system. Completed questionnaires were checked and entered into SPSS Version 10.0 for cleaning and statistical analyses. The machine (computer) readable data file is available for distribution to interested researchers or graduate degree students wishing to do secondary data analyses. Upon written request to the ECS Office,



researchers will be given a "SPSS File Information Document," and either a CD-Rom, or 3.5 diskette as provided by the researcher. To maintain confidentiality there are no personal identifiers.

3. **Focus Group Interviews.** During survey data collection, respondents were asked if they would participate in a focus group. PLWHAs were also asked if they would solicit someone from their care-giver support network. The project also solicited known care-givers of persons who had died to be sure we obtained input from persons familiar with all stages of this disease.

Three focus groups were conducted as breakfast sessions held in a private room at a hotel restaurant during the month of November 2002. Sessions were tape recorded (using an eight line, multi-microphone machine), with an observer making written notes as well as the facilitator.

#### **Number of participants:**

The first session of PLWHA was composed of six (6) participants, the second session had fifteen (15) service provider participants, and the third session was composed of eight (8) family/friend care-givers. Tapes of all three focus groups were transcribed, edited to remove personal names or identifiers and typed placing respondent quotes in bulleted list fashion under each of the questions and probes that were asked during each session.

#### **Analysis:**

The session transcriptions were analyzed by a team of five (5) reviewers, composed of project staff from the Coral Life Foundation and the University. Participant comments were cut into strips that could be sorted by each reviewer, who first individually identified major themes and issues expressed by participants in each session. The team then met as a group to develop a collective consensus on the themes and issues. Three meetings were held, one for each session. Themes identified in each group were then compared and given comparable "header" labels where common themes were expressed in the different groups. The final analyses for each focus group with representative participant quotes are displayed in this report.

#### **How to read the presentation of Tables and Charts:**

Data counts of persons living with HIV/AIDS who were receiving services obtained from the service provider survey are displayed in Table 1. Tables 2 through 10 display frequency percentage distributions for questions on the PLWHA survey, as sequenced in the questionnaire. These were tabulated for the total of all respondents, and separately by gender (male or female), and by care status (diagnosed with HIV only, or diagnosed with AIDS).

Graphic charts were produced corresponding to Tables 2 through 10. These were numbered according to their corresponding table. Thus, Chart 2a, 2b, and 2c correspond to Table 2, and in similar fashion, Charts 3a, 3b, 3c, 3d, 3e correspond to Table 3.

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## **Demographic Profile of Persons Living With HIV/AIDS**

### **National And Official Guam Statistical Data**

A major issue raised in the first Guam HIV/AIDS Consortia, held April 26, 2002, was the community's lack of knowledge on the actual number of persons living with HIV/AIDS (PLWHA) on Guam and the nature of their needs for care and assistance. It is widely accepted that the existing system for record keeping of persons testing positive for HIV infection, and of persons diagnosed with AIDS, does not provide a complete picture of events on island. Yet, Guam's system of HIV/AIDS testing data collection, and its inclusion in the national surveillance system does produce insightful and useful comparisons. One aim of the needs assessment study and purpose of this document was to provide the community with useful information helping them gain a common understanding of the social dimensions and human situations of the disease on island. To facilitate this, recent national and official Guam statistical data have been presented here to provide readers with background information in addition to the findings of the needs assessment study.

For the year 2000, the national surveillance system for recording and tabulating HIV/AIDS cases published that Guam reported 13 cases of diagnosed AIDS (see Chart A). These 13 cases, given Guam's small population, produced an AIDS rate (12.9 per 100,000) higher than the State of Hawaii (11.4). However, the 114 reported AIDS diagnoses in Hawai'i ranked it as 39th out of the 55 US states and territories, California's 4,688 cases ranked it 3rd, and Puerto Rico's 1,345 cases ranked it 9th. Guam's 13 cases ranked it 51st, while the 34 cases reported for the Virgin Islands ranked it as 46th out of the 55 states and territories. Guam's low numbers rank it as a jurisdiction with low priority in the competition for U.S. federal dollars and national attention. Yet the national statistics also give supportive evidence of where Guam has legitimate issues to be addressed in the nation's agenda. Additional data from this national surveillance statistical report presented in Charts B-1 through C-2 illustrate this idea. AIDS cases among women on Guam in 2000 rank higher nationally than AIDS cases among men (see Charts B1 and 2). Looking at Charts C1 and 2, Guam ranks higher nationally if the focus is on aggregated data for "Asian and Pacific Islanders" (rank 16-17 out of 55). Even so, California (rank 1) and Hawaii (rank 3) simply have larger Asian/Pacific Islander populations in-need.

Guam's HIV Surveillance Reports (see Chart D-1), and its AIDS Surveillance Reports (see D-2) provide insightful data on the demographic profile of persons on Guam testing HIV positive and being diagnosed with AIDS. This data is also tabulated into a United Nations, World Health Organization report (see Chart D-3). These reports are accurate tabulations of people "testing" or being "diagnosed" on Guam. However, these reports do not account for persons living on Guam who were tested or have been diagnosed off-island, nor for the migration of PLWHA's moving on-island and those moving off-island.

### **Survey of Service Providers**

The service providers who responded included medical care physicians from the Guam Medical Society and the project's Advisory Council (N=14), as well as social service and resource programs (10 public and community-based non-government organizations). Although we assumed the physicians would provide an unduplicated count, one physician clarified that he had only been consulted as a specialist, when we asked him to contact his patient. The patient he listed on his survey had accepted an HIV test as he attempted to diagnose presenting symptoms in the patient's urinary track. This means



that there may be one (1) duplicate count among the 48 patients tabulated from the physicians as shown in Table 1.

Table 1 displays the counts of PLWHA receiving services on Guam obtained from a wide range of service providers on island. Primary care medical doctors reported having 25 persons with HIV and 23 persons diagnosed with AIDS. The service and resource programs reported having 41 persons with HIV and 19 with AIDS. Given what is known about PLWHA and use of services, the pattern displayed can be expected. There are those PLWHA who do not seek primary care of a physician until they have presenting symptoms requiring medical attention. As found, physicians reported a smaller number of persons under their care, yet a larger proportion (23 = 48%) were persons diagnosed with AIDS. In comparison, the service programs reported a larger number of clients, and a notably lower proportion of this count were clients with AIDS (about one-third: 19 of 60). It is known that due to the lack of sufficient care services on Guam, PLWHA move off-island, or commute off-island if they can afford the travel, to access a wider array of services they need. One of the PLWHA who participated in this study's focus group moved off-island shortly there-after for this very reason. He stated in the focus group, "I'm relocating to California because of problems with MIP, and the physicians here on Guam are not really qualified. I am afraid with all the problems going here on Guam" (see statements from the PLWHA focus group #1, section on "Case Management Needs").

Service providers were also asked where their PLWHA patient consumers were tested, and this question was included as well in the survey of PLWHA. Displayed in the mid panel of Table 1, data from the service providers give an estimate that about 30 percent of PLWHA receiving services on Guam actually tested for their disease condition off-island. This is the mid-point between the information reported by physicians (25% of patients tested off-island) and the data reported by the service programs (35% tested off-island). In the lower panel of Table 1, the PLWHA survey data separated the question to specify where they tested for HIV versus where they tested for AIDS. Both were examined for differences by gender. Looking at the far right column for all respondents (Total), the study found that about one-out-of-five reported testing off-island. Among those who tested for AIDS a slightly greater proportion tested off-island (21% tested for AIDS off-island versus 18% tested HIV+ off-island). Because all of the female PLWHA who responded only had testing on-island, this evidence was stronger among male PLWHA (i.e., 23% of males tested HIV positive off-island, but among those who have tested for AIDS, 30% had the testing off-island).

### **Estimates of Persons Living With HIV/AIDS on Guam**

From the information collected, the data suggest that Guam's official number counts of HIV/AIDS cases that are based upon persons testing on-island, may only account for about 70 percent of the number of persons on-island in need of services. The evidence suggests that this discrepancy is most likely greater for counts of persons testing for AIDS (than for HIV). The tabulation from the physicians provided this study's best estimate of an unduplicated count, and as such was applied as a being a conservative low estimate of current number of persons in need of services (N=48). The tabulated count from agencies and NGO programs provide the study's best but also conservative, mid-level estimate of PLWHA in need of services (N=60). It is assumed that there is some degree of error for each of these estimates. The PLWHA survey finding that about one-fifth of the island's actual number of PLWHA may not have even been contacted by this study because they are not currently in-need of any services (see Table 3), would increase the mid-level estimate upward by as many as 16 persons. Using this finding as the estimated proportion of PLWHA on island not accessing any services, a liberal high estimate of PLWHA on Guam would be about 76 persons.



We emphasize the very serious caution that these estimates are speculative. The number of persons living with HIV/AIDS is estimated to extend from at least 48 PLWHA currently in need of primary medical care, to a mid-level estimate of about 60 PLWHA in need of social services and some primary care, to a high end estimate of about 76 PLWHA which includes PLWHA not using or not yet in need of services

### **Basic Demographics and Stages of The Disease**

Half of the PLWHA who responded had been diagnosed as having AIDS, and half remained at their initial HIV positive care status (see Table 2 and Charts 2a - 2c). Consistent with the epidemiologic profile, the majority of respondents were male (22 of 28), with age extending across the range of years since they tested positive. About two out of five males (41%) tested positive in the last 5 years (1998-2002), and one out of seven (14% of males) reported they tested positive ten to 16 years ago in the time period 1986-1992. This was the initial time period when testing was initiated on Guam (Annual CPG report reference). Also consistent with Guam's Epidemiologic Profile, over half of the respondents were Chamorro (57%), with Micronesians (18%) being the next largest ethnic group. Fewer female PLWHA responded, and more of them reported testing positive in these early years (33%) 1986-92 than males. Respondents did not include any female who tested positive more recently (1998-2002). One "respondent" was under 17 years old (a child), with about half of males (55%) and half of females (50%) age 36 years or older.

### **Access to care and use of services**

Respondents were representative of the full spectrum of PLWHA on Guam, by age, ethnicity, care status, and length of time since tested positive, and as displayed in Table 3, those who responded to this needs assessment were persons accessing social and medical services on Guam. A majority (82%) were accessing primary care on Guam. Yet, the corollary to this is that about one-out-of-five (18%) were not.

Care status, defined as having been diagnosed with AIDS, was found to be a factor in patterns of accessing primary care and use of services (see Table 3 and Charts 3a-3e). The comparison of respondent information by care status found that persons at a later stage of the disease (i.e., having been diagnosed with AIDS) were more likely to report they were not accessing primary care on Guam (21% no, versus only 15% of those still HIV only), and more likely to be accessing off-island service providers (29% of AIDS diagnosed compared to 21% of HIV care status). Also, persons diagnosed with AIDS were the only respondents who reported that their primary care was an off-island doctor (17%). Persons in early stages of the disease were the only respondents (about half, 43%) who reported they have not yet used any of the five main agencies and programs serving PLWHA on Guam. Over two-thirds (72%) of persons diagnosed with AIDS reported they have used services at several or all of these organizations compared to only one-third of persons not diagnosed with AIDS.

This study found that persons diagnosed with AIDS were more likely to report having problems with referrals to specialists (71%), than persons whose care status still remains HIV positive (see Table 5 and Charts 5a - 5c). Among the PLWHA who responded to the survey, only one HIV positive respondent indicated they had a problem where there was no specialist on-island. About one-third (29%) of PLWHA diagnosed with AIDS indicated having payment problems. One-third (33%) of all respondents indicated they have had communication problems with service providers, but the corollary

is that most have not had such difficulty. There was no difference in reported communication problems by gender nor by care status.

If you look at Chart 5c (the bottom panel of Table 5), the study found that about half of PLWHA who responded (46%) only feel comfortable revealing their HIV status to their primary care service providers. Again, care status was found to be a notable factor. A greater proportion of those diagnoses with AIDS (43%) felt comfortable revealing their HIV status to “anyone” compared to only one (7%) of the persons who were still only HIV positive.

### **Basic Demographics: Employment and Finances**

Of the PLWHA who responded, about half were employed (46%) and one-fourth (25%) were on Social Security, disability, retirement, – or a dependent minor (See Table 6 and Chart 6a). Near equal numbers of the remaining PLWHA were unemployed and either looking for work/applying for disability (18%), or just unemployed and not looking for work (11%). PLWHA were specifically asked if they received any kinds of income or financial assistance, and similar to the employment question, half (50%) reported they did not receive any financial aid assistance. Of those reporting they received some kind of income assistance, one-third of all respondent PLWHA reported things such as rent/housing assistance, food stamps, SS/disability and other entitlements. A smaller number (18%) reported that the only financial assistance they received was for their HIV/AIDS medications.

Medications were being paid for in several ways, and some PLWHA reported they were not on medications (14%). In response to another question several indicated they were “Early stage, no medical bills” (11%). The most frequent sources of payment were insurance (35%) and Medicaid/Medicare along with Guam’s Medical Indigent Program (29%). Several PLWHA reported that they are unable to pay for medications (4%) or unable to pay medical bills (7%).

The survey asked for income and monthly expenses, yet the question format was definitely one weakness affecting the number of responses and nature of the information given (see Appendix C). Only seventeen respondents (61%) gave usable information, and it was apparent in the nature of responses that individuals were unclear about what was being requested. Even so, the data has been presented in this report for several reasons: first, there are some insights suggested by the information that was given, and second, any future needs assessment study will be able to assess exactly what kind of information is needed for this type of analysis and how to ask the questions.

The information on income and expenses was tabulated separately for those reporting they did receive public financial assistance versus those who did not (see Table 7 and Charts 7a – 7c). Those who did not receive public assistance reported a higher average monthly “income” (\$1,879.) than those who qualify for and received some kind of welfare or income assistance (\$1,530.). This is at least consistent with an “expected” response pattern. Even so, we cautiously note that the data revealed monthly expenses for major necessities (housing, health care and medications) consumed a much greater proportion of monthly income for PLWHA who qualify for public assistance (84% of monthly income), than other PLWHA (32% of monthly income).

### **Basic Demographics: Living Situations and Relationships**

Over half of the responding PLWHA (53%) live in their own home or rented apartment (see Table 8 and Chart 8a). Another three respondents (11%) stated they rent a room or space in someone else’s dwelling. The data indicate most (two-thirds) of the PLWHA who responded were secure in



owning or being able to pay for housing at the time of this survey. This living situation was reported by all of the women PLWHA who responded. The corollary is that about one-third of PLWHA, who happened to be all males, were not having to pay for housing. Most of these (28%) reported they stayed without cost with friends or family, one respondent (4%) was at the time of data collection in a correctional facility, and one (4%) reported being homeless at the time of data collection.

Homelessness had been experienced, however, by about one-third (29%) of the surveyed PLWHA, most of whom were male (see lower panel of Table 8 and Chart 8c1). Half of those who had experienced homelessness, had been homeless for more than one week over the past three years. Nearly one-out-of-five PLWHA (19%), again all males, reported having difficulty obtaining housing. Reasons included their own substance abuse, bad credit/affordability, or transportation problems. These same five (5) also responded affirmative to the survey question asking if they had ever felt discrimination in trying to get housing. A majority of the PLWHA surveyed (over 80%) reported they had never felt discrimination in trying to get housing or other difficulties getting housing.

The survey included a boxed set of paired statements about preferred housing that attempted to identify preferences of PLWHA for different kinds of Just like the question on monthly income and expenses, unfortunately, the question format did not work as hoped (see Appendix C). Respondents did mark statement pairings, and two were selected for presentation in this report. One pair had respondents choose between “living with family/friends” versus “living with other PLWHA”; and the other pair had them choose between living in a “building with daily services” versus one where “services are external or separate of housing” (see Table 8 and charts 8b1-2). Interpreting the responses suggests that PLWHA may have seen these questions as a way to say that if they could do it, their ideal preference would be to live with family/friends (selected by 70%) in a normal household setting where services were external or separate of housing (selected by 74%).

### **Ratings of service needs**

The PLWHA survey instrument had a question section at the end which listed thirty-five (35) services grouped into nine groupings (see Appendix C). For each service Respondents were to mark: A) “The importance to you” [ response choices of (3) High, (2) Medium (1) Low], B) “Do you know if it’s available currently,” [ Yes, No, Don’t Know], and C) Have you accessed it on Guam,” and D) Have you accessed it off-island?” [Yes or No]. A “Mean” or average Service Importance score ranging from 3 = high importance to 1 = low importance was calculated for each service. Due to the small number of respondents (N=28) and the low numbers of PLWHA who accessed any particular service off-island or on-island, these responses were combined together into a single measure of “accessed the service.” Responses on “Importance Ranking” of services have been displayed in Tables 4a-b, and responses on “Perceived Availability” and “Attempted Access” have been displayed in Tables 9 and 10 (see Charts 9a-c, and 10a-d).

All services should be considered important, and this study’s analyses should not be misunderstood or misconstrued to imply that any service is not important. As shown in Tables 4 a and b, the needs assessment study found that the top priority needs of PLWHA to be “general” medical needs (i.e., lab work, appointments, early stage care, dental work, late stage care); Financing medical costs (i.e., medical costs, treatment costs, financial support), and Case Management needs (i.e., service coordination, treatment advocacy, information & referral, legal services). The study also found that persons diagnosed with AIDS rated the importance of services in these three top priority areas higher than ratings by persons who were still HIV positive.

The study found that several types of counseling considered to be important psycho-social services (i.e., higher mean importance ratings) were also services where "perceived availability" was lower than attempted access (see Table 9). This is interpreted to reveal that more PLWHA have sought out and attempted to access these types of services than the number of PLWHA who feel such services are available to them. Specifically, perceived availability was lower than attempted access of Support Group counseling by Female PLWH (33% compared to 67%), and by PLWHA diagnosed with AIDS (36% compared to 42%). Perceived availability was lower than attempted access of Emotional/practical counseling by Male PLWH (9% compared to 19%), and by PLWHA diagnosed with AIDS (7% compared to 23%). Perceived availability was lower than attempted access of Support Group counseling by Female PLWH (33% compared to 67%), and by PLWHA diagnosed with AIDS (36% compared to 42%). Also, perceived availability was lower than attempted access of Family counseling by PLWHA diagnosed with AIDS (25% compared to 36%). The implied finding is that Support group counseling, Emotional/Practical Counseling, and Family Counseling are three types of psycho-social needs where service availability is lower than service need and demand by PLWHA on Guam who have been diagnosed with AIDS and are at a later stage of care needs. The paucity of Support group counseling was a particular need problem for Female PLWHA, and the paucity of Emotional/practical counseling was a particular need problem of Male PLWHA.



**Charts A – C: AIDS CASES FOR SELECTED TERRITORIES AND STATES: 2000**

**Chart A: Comparison Of Aids Diagnosis Among Adults And Adolescents In Select US Affiliated Areas: 2000<sup>1</sup>**

		Area Of Residence At AIDS Diagnosis <sup>2</sup>					
		Guam	Pacific Islands	Hawaii	California	Puerto Rico	Virgin Islands
<b>AIDS cases reported</b>							
	No.	13	0	114	4,688	1,345	34
	Rank <sup>3</sup>	51	—	39	3	9	46
<b>AIDS rate<sup>4</sup></b>							
	Rate	12.9	0	11.4	17.3	44.5	42.4
	Rank	23	—	26	18	2	3

**Chart B-1: Comparison Of Aids Diagnosis Among Adult And Adolescent Men In Select US Affiliated Areas: 2000**

		Area Of Residence At AIDS Diagnosis					
		Guam	Pacific Islands	Hawaii	California	Puerto Rico	Virgin Islands
<b>AIDS cases: Men</b>							
	No.	11	0	100	4,060	966	23
	Rank	51	—	39	2	9	47

**Chart B-2: Comparison Of Aids Diagnosis Among Adult And Adolescent Women In Select US Affiliated Areas: 2000**

		Area Of Residence At AIDS Diagnosis					
		Guam	Pacific Islands	Hawaii	California	Puerto Rico	Virgin Islands
<b>AIDS cases: Women</b>							
	No.	2	0	14	628	379	11
	Rank	49	—	41	3	9	43

<sup>1</sup> Center for Disease Control and Prevention. AIDS Cases by State and Metropolitan Area of Residence, 2000, HIV/AIDS Surveillance Supplemental Report, 2000;8 (No.2)  
[online <http://www.cdc.gov/hiv/status/hasrsupp.htm>]

<sup>2</sup> Area of Residence At AIDS Diagnosis is the location where the testing was conducted and documented, not where the person lives. Persons from Guam who travel to Hawaii for testing are recorded under Hawaii

<sup>3</sup> Rank was assigned based on 55 areas –states and territories, lowest rank =highest magnitude

<sup>4</sup> Rate per 100,000 population

**Chart C-1: Comparison Of Aids Diagnosis Among Adult And Adolescent Asian/Pacific Islander Men In Select US Affiliated Areas: 2000**

		Area Of Residence At AIDS Diagnosis					
		Guam	Pacific Islands	Hawaii	California	Puerto Rico	Virgin Islands
<u>Men</u>							
AIDS cases through 2000							
	No.	31	2	572	2,236	1	1
	Rank	16	42	3	1	46	46
AIDS cases in 2000							
	Rate	8	0	34	96	0	0
	Rank	8	—	3	1	—	—
Prevalence at end of 2000							
	No.	17	1	211	1,023	0	0
	Rank	17	43	3	1	—	—

**Chart C-2: Comparison Of Aids Diagnosis Among Adult And Adolescent Asian/Pacific Islander Women In Select US Affiliated Areas: 2000**

		Area Of Residence At AIDS Diagnosis					
		Guam	Pacific Islands	Hawaii	California	Puerto Rico	Virgin Islands
<u>Women</u>							
AIDS cases through 2000							
	No.	5	2	73	261	0	0
	Rank	17	31	3	1	—	—
AIDS cases in 2000							
	Rate	2	0	8	18	0	0
	Rank	8	—	2	1	—	—
Prevalence at end of 2000							
	No.	5	1	32	149	0	0
	Rank	13	30	3	1	—	—

**Chart D-1: HIV Surveillance Report**  
**Guam Department of Public Health & Social Services Cases to March 11, 2003**

Year of Report	1985-95	1996	1997	1998	1999	2000	2001	2002	Total
Cases by Year	81	15	10	15	11	7	29	5	173
Rate per 100,000	N/A	10.35	7.5	10.7	7.23	4.5	18.4	3.1	N/A

Risk Category	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
<b><u>GENDER</u></b>									
Male	71 (88)	11 (73)	7 (70)	13 (87)	9 (82)	7 (100)	27 (93)	4 (80)	149 (86)
Female	10 (12)	4 (27)	3 (30)	2 (13)	2 (18)	0	2 (7)	1 (20)	24 (14)

<b><u>AGE</u></b>									
<13	0	0	0	0	1 (9)	0	0	0	1 (<1)
13-19	2 (2)	0	1 (10)	0	0	0	0	0	3 (2)
20-29	33 (41)	3 (20)	1 (10)	3 (20)	0	1 (14)	14 (48)	2 (40)	57 (33)
30-39	32 (39)	10 (67)	5 (50)	6 (40)	6 (55)	3 (43)	13 (45)	1 (20)	76 (44)
40-49	9 (11)	2 (13)	2 (20)	3 (20)	4 (36)	3 (43)	1 (3)	2 (40)	26 (15)
>49	3 (4)	0	1 (10)	3 (20)	0	0	1 (3)	0	8 (5)
Unknown	2 (2)	0	0	0	0	0	0	0	2 (1)

<b><u>RACE</u></b>									
Chamorro	42 (52)	9 (60)	9 (60)	4 (27)	7 (64)	4 (57)	3 (10)	3 (60)	76 (44)
Filipino	5 (6)	1 (7)	1 (7)	1 (7)	2 (18)	0	0	1 (20)	10 (6)
Caucasian	20 (25)	3 (20)	3 (20)	4 (27)	1 (9)	1 (14)	1 (3)	0	32 (19)
Black	4 (5)	2 (13)	2 (13)	1 (6)	1 (9)	0	0	0	7 (4)
FAS	3 (4)	1 (8)	2 (20)	3 (20)	1 (9)	1 (14)	0	1 (20)	11 (6)
Other PI	0	0	2 (20)	0	0	1 (14)	1 (3)	0	4 (2)
Asian	2 (2)	0	0	0	0	0	22 (76)	0	24 (14)
Other	5 (6)	2 (17)	0	0	0	0	2 (7)	0	9 (5)

<b><u>RISK</u></b>									
MSM	42 (52)	7 (46)	5 (50)	8 (53)	7 (64)	5 (72)	5 (17)	2 (40)	81 (47)
IDU	4 (5)	1 (7)	0	0	0	1 (14)	0	0	6 (4)
MSM/IDU	2 (2)	0	0	0	1 (9)	0	0	0	3 (2)
Female	8 (10)	4 (27)	2 (20)	1 (7)	2 (18)	0	1 (3)	1 (20)	19 (11)
Male	8 (10)	1 (7)	2 (20)	2 (13)	0	0	22 (76)	2 (40)	37 (21)
Transfusion	2 (2)	0	0	0	0	0	1 (3)	0	3 (2)
Hemophiliac	3 (4)	0	0	0	0	0	0	0	3 (2)
Perinatal	0	0	0	0	1 (9)	0	0	0	1 (<1)
Other	0	0	0	1 (7)	0	0	0	0	1 (<1)
Unknown	12 (15)	2 (13)	1 (10)	3 (20)	0	1 (14)	0	0	19 (11)

**Note:** HIV data inclusive of AIDS cases up to December 2002.

**Chart D-2: AIDS Surveillance Report**  
**Guam Department of Public Health & Social Services    Cases to December 2002**

Year of Report	<u>1985-95</u>	<u>1996</u>	<u>1997</u>	<u>1998</u>	<u>1999</u>	<u>2000</u>	<u>2001</u>	<u>2002</u>	<u>TOTAL</u>
Cases by Year	32	10	5	7	8	2	8	4	76
Rate per 100,000	N/A	6.9	3.41	4.69	5.26	1.29	4.9	2.5	N/A
<b>Risk Category</b>	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
<b><u>GENDER</u></b>									
Male	30 (94)	9 (90)	4 (80)	6 (86)	7 (88)	2 (100)	8 (100)	4 (100)	70 (92)
Female	2 (6)	1 (10)	1 (20)	1 (14)	1 (12)	0	0	0	6 (8)
<b><u>AGE</u></b>									
<13	0	0	0	0	0	0	0	0	0
13-19	0	0	0	0	0	0	0	0	0
20-29	10 (31)	1 (10)	0	2 (29)	0	0	2 (25)	0	15 (16)
30-39	15 (47)	6 (60)	4 (80)	3 (43)	4 (50)	1 (50)	4 (50)	1 (25)	38 (53)
40-49	4 (13)	3 (30)	1 (20)	1 (14)	3 (37)	1 (50)	1 (12.5)	3 (75)	17 (24)
>49	3 (9)	0	0	1 (14)	1 (13)	0	1 (12.5)	0	6 (7)
<b><u>RACE</u></b>									
Chamorro	19 (59)	8 (80)	4 (80)	3 (44)	6 (75)	1 (50)	3 (37.5)	2 (50)	46 (60)
Filipino	3 (9)	0	0	0	1 (12.5)	0	0	0	4 (5)
Caucasian	7 (22)	1 (10)	1 (20)	2 (28)	1 (12.5)	0	1 (12.5)	0	13 (17)
Black	2 (6)	1 (10)	0	0	0	0	0	0	3 (4)
FAS/PI	0	0	0	2 (28)	0	1 (50)	3 (37.5)	2 (50)	8 (11)
Asian	1 (3)	0	0	0	0	0	1 (12.5)	0	2 (3)
<b><u>RISK</u></b>									
MSM	18 (56)	5 (50)	3 (60)	4 (57)	6 (75)	1 (50)	6 (75)	3 (75)	46 (60)
IDU	3 (9)	1 (10)	0	0	0	1 (50)	0	0	5 (7)
MSM/IDU	0	0	0	0	0	0	0	0	0
Female	2 (6)	1 (10)	1 (20)	1 (14)	1 (12.5)	0	0	0	6 (8)
Male	1 (3)	1 (10)	1 (20)	1 (14)	0	0	2 (25)	1 (25)	7 (9)
Transfusion	2 (6)	0	0	0	0	0	0	0	2 (3)
Hemophiliac	3 (9)	0	0	0	0	0	0	0	3 (4)
Perinatal	0	0	0	0	0	0	0	0	0
Unknown	3 (9)	2 (20)	0	1 (14)	1 (12.5)	0	0	0	7 (9)

\* Data as of 12/2002

**BUREAU OF COMMUNICABLE DISEASE CONTROL, 123 Chalan Kareta, Route 10,  
Mangilao, Guam 96923  
(671) 735-7311, 734-2437 (Fax)**



### Chart D-3: Official Guam HIV and AIDS Case Report

Updated report includes cases cumulative to: 12/21/02

Country: Guam

CUMULATIVE TOTAL					
Sum of the reported cases since the 1st case reported in 1985					
AGE	HIV		AIDS		
	Male	Female	Male	Female	
less than 5 years	1	0	0	0	
5 to 9 years	0	0	0	0	
10 to 14 years	0	0	0	0	
15 to 19 years	3	1	0	0	
20 to 24 years	15	10	4	1	
25 to 29 years	27	3	9	1	
30 to 34 years	41	1	20	1	
35 to 39 years	25	4	15	3	
40 to 44 years	11	3	8	0	
45 to 49 years	10	2	8	0	
50 years and older	8	0	6	0	
Unknown age	8	0	0	1	
TOTALS by sex	149	24	70	7	
TOTALS	173		77		
			AIDS Deaths	41	4

CUMULATIVE TOTAL					
Sum of the reported cases since the 1st case reported in 1985					
	HIV		AIDS		
	Male	Female	Male	Female	
Mother to child transmission	1	0	0	0	
Injecting drug use	8	1	6	0	
Homosexual/Bisexual transmission	80	0	49	0	
Blood or blood	5	0	4	0	
Heterosexual	16	18	7	6	
Other known mode of	0	1	1	0	
Unknown mode of	39	4	3	1	
TOTALS by sex	149	24	70	7	
TOTALS			173	77	
			AIDS Deaths	41	4

**Table 1: Numbers Of Persons Living With HIV/AIDS on Guam and Where They Tested:  
Surveys of Service Providers and Person with HIV/AIDS**

Service Providers Surveys			
	Medical Care <u>Physicians</u>		<u>Agency Service</u>
Reported Number of	(N=14)		(N=10)
Persons HIV+	25		41
Persons with AIDS	<u>23</u>		<u>19</u>
Total	48		60
Where Tested	Medical Care <u>Physicians</u>	<u>(Total)</u>	<u>Agency Service</u>
On-Island	36	(75)	39
Off-Island	12	(33)	21
Percent Off-Island	25%	(31%)	35%
Persons With HIV/AIDS Survey			
Where Tested	Male	Female	Total
<u>For HIV Diagnosis</u>	(N=22)	(N=6)	(N=28)
On-Island	77%	100%	82%
Off-Island	23%	0	18%
<u>For AIDS Diagnosis</u>	<u>(N=10)</u>	<u>(N=4)</u>	<u>(N=14)</u>
On-Island	70%	100%	79%
Off-Island	30%	0	21%

**TABLE 2: Demographic Profile Of Persons Living With HIV/AIDS (PLWHA) Who Responded To The Survey\***

<b>Profile Traits</b>	<b>Total</b>	<b>Male</b>	<b>Female</b>
<b><u>Year Learned of Status HIV/AIDS</u></b>	<b><u>(N=28)</u></b>	<b><u>(N=22)</u></b>	<b><u>(N=6)</u></b>
1986-92	18%	14%	33%
1993-97	50%	45%	67%
1998-02	<u>32%</u>	<u>41%</u>	<u>0%</u>
	100%	100%	100%
<b>Care Status:</b>			
<b><u>Diagnosed with AIDS</u></b>			
No	50%	54%	33%
Yes	<u>50%</u>	<u>45%</u>	<u>67%</u>
	100%	100%	100%
<b><u>Age</u></b>	<b><u>(N=28)</u></b>	<b><u>(N=22)</u></b>	<b><u>(N=6)</u></b>
Under 17 years	4%	4%	0
18 to 35 years	43%	41%	50%
36 to 55 years	<u>53%</u>	<u>55%</u>	<u>50%</u>
	100%	100%	100%
<b><u>Ethnicity</u></b>			
Chamorro	57%	50%	83%
Micronesian	18%	23%	0%
Statesider	14%	13%	17%
Filipino/Asian	<u>11%</u>	<u>14%</u>	<u>0%</u>
	100%	100%	100%

**Table 3: Percent of PLWHA Accessing Primary Care and Agency Services On Guam**

Primary Care on Guam	Total (N=28)	Gender		Care status	
		Male (N=22)	Female (N=6)	HIV (N=14)	AIDS (N=14)
No	18	19	17	15	21
Yes	<u>82</u>	<u>81</u>	<u>83</u>	<u>85</u>	<u>79</u>
	100%	100%	100%	100%	100%
<b>Used Off-Island Service Providers</b>					
Yes	25	23	33	21	29
No	<u>75</u>	<u>77</u>	<u>67</u>	<u>79</u>	<u>71</u>
	100%	100%	100%	100%	100%
<b>Where do you Access Care</b>					
Public Health	56	53	66	78	42
On-Island Physician	24	27	17	11	33
Off-Island Physician	10	13	0	0	17
On and Off Island	<u>10</u>	<u>7</u>	<u>17</u>	<u>11</u>	<u>8</u>
	100%	100%	100%	100%	100%
<b><u>Number Out of 5 Guam</u></b>					
<b><u>Service Agencies Ever Used</u></b>					
None of these	21	27	0	43	0
Only One	25	27	17	21	28
Two-Three	32	32	33	29	36
Four-Five	<u>22</u>	<u>14</u>	<u>50</u>	<u>7</u>	<u>36</u>
	100%	100%	100%	100%	100%
<b>Percent YES, Used Agency For Service</b>					
1. Public Health & Social Services	75%	68%	100%	57%	93%
2. Guam Memorial Hospital	46%	46%	50%	21%	71%
3. Coral Life Foundation	43%	36%	67%	21%	64%
4. Guam Housing & Urban Renewal	21%	14%	50%	7%	36%
5. Mental Health & Substance Abuse	11%	5%	33%	7%	14%



**Table 4a: Summary Grouping of Service Needs-Mean "Importance"**

<u>Rank #. Category</u>	<u>Services:</u>	<u>Mean Scores</u>		
		<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
<b>Medical Treatment Needs (General)</b>	Lab Work *	2.93	2.85	3.00
	Appointment * (sig.)	2.86	2.71	3.00
	Early Stage Care *	2.86	3.00	2.71
	Intermediate Stage Care	2.78	2.71	2.85
	Dental Care	2.59	2.38	2.79
	Late Stage Care	<u>2.59</u>	<u>2.50</u>	<u>2.69</u>
	<b>Medical Average:</b>	<b>2.8</b>	<b>2.7</b>	<b>2.8</b>
<b>Financing Medical Costs</b>	Medical Costs *	2.82	2.64	3.00
	Treatment Costs*	2.82	2.64	3.00
	Financial Support *( sig.)	<u>2.62</u>	<u>2.23</u>	<u>3.00</u>
	<b>Financing Costs Average:</b>	<b>2.7</b>	<b>3.0</b>	<b>3.0</b>
<b>Case Management Needs (Service coordination, information &amp; referrals)</b>	Service Coordination	2.71	2.50	2.93
	Treatment Advocacy *(sig.)	2.68	2.43	2.93
	Information & Referral *(sig.)	2.64	2.29	3.00
	Legal Services *	<u>2.61</u>	<u>2.36</u>	<u>2.86</u>
	<b>Case Mgt. 1 Average:</b>	<b>2.7</b>	<b>2.4</b>	<b>3.0</b>
<b>Educational Issues and Information Needs of PLWHA and their caregivers</b>	<u>Resource Guide</u>	<u>2.61</u>	<u>2.50</u>	<u>2.71</u>
	Nutrition	2.57	2.57	2.57
	Printed Information	2.57	2.36	2.79
	Hotline	<u>2.21</u>	<u>2.14</u>	<u>2.29</u>
	<b>Case Mgt. 2 Average:</b>	<b>2.5</b>	<b>2.4</b>	<b>2.6</b>
<b>Case Management Needs (Daily Life and Housing Assistance)</b>	Transportation	2.57	2.43	2.71
	Housing	2.50	2.43	2.57
	Long-term housing	2.50	2.36	2.64
	Fiscal Mgt. (budgeting)	2.26	2.15	2.36
	Employment Assistance	2.36	2.50	2.21
	Rental Assistance	2.32	2.29	2.36
	Transitional Housing	2.07	2.36	1.79
	Child Care	<u>1.54</u>	<u>1.64</u>	<u>1.43</u>
	<b>Case Mgt. 3 Average:</b>	<b>2.3</b>	<b>2.3</b>	<b>2.3</b>
<b>Medical Needs Late Stage</b>	Late Stage-Hospice	2.41	2.38	2.43
	Late Stage- Burial	2.41	2.38	2.43
	Alternative/Traditional	2.28	2.00	2.54
	Late Stage-Skilled Nursing	<u>2.26</u>	<u>2.15</u>	<u>2.36</u>
	<b>Medical Average:</b>	<b>2.3</b>	<b>2.2</b>	<b>2.4</b>
<b>Psycho-Social Issues (Mental Health)</b>	Support Group Counseling	2.44	2.43	2.46
	Emotional /Practical	2.36	2.29	2.43
	Individual Counseling	2.22	2.07	2.38
	Family Counseling	1.93	1.79	2.08
	Couple Counseling	1.77	1.79	1.75
	Substance Abuse Counseling	<u>1.71</u>	<u>1.79</u>	<u>1.64</u>
	<b>Psycho-social Average:</b>	<b>2.1</b>	<b>2.0</b>	<b>2.1</b>

\*Statistical significant difference between means for HIV only versus with AIDS using SPSSF-test  $p < .01$  Those marked (sig.) are stronger with t-test verification of the assumption for equal variances

Table 4b: Summary Grouping of Service Needs - Mean “Importance” Score

<u>Rank #. Service Need Category</u>		<u>Mean Scores</u>		
		<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
Medical Treatment Needs (General)	Average:	2.8	2.7	2.8
Financing Medical Costs	Average:	2.7	2.4	3.0
Case Management Needs (Service coordination, information & referrals)	Average:	2.7	2.4	3.0
Educational Issues/ Information Needs of PLWHA and their caregivers	Average:	2.5	2.4	2.6
Case Management Needs (Daily Life and Housing Assistance)	Average:	2.3	2.3	2.3
Medical Needs Late Stage	Average:	2.3	2.2	2.4
Psycho-Social Issues (Mental Health)	Average:	2.1	2.0	2.1

**Table 5: Reported Problems With Services And Comfort Revealing HIV Status To Others**

<u>Problem With Specialist Referral</u>	<u>Total</u> <u>(N=28)</u>	<u>Gender</u>		<u>Care Status</u>	
		<u>Male</u> <u>(N=22)</u>	<u>Female</u> <u>(N=6)</u>	<u>HIV</u> <u>(N=14)</u>	<u>AIDS</u> <u>(N=14)</u>
No	46%	55%	17%	64%	29%
Yes – None On-Island	4%	5%	0%	7%	0%
Yes – Payment Problem	14%	13%	17%	0%	29%
Yes - Other	<u>36%</u>	<u>27%</u>	<u>66%</u>	<u>29%</u>	<u>42%</u>
	100%	100%	100%	100%	100%

**Problem Communicating with Service Providers**

No	67%	67%	67%	69%	64%
Yes	33%	33%	33%	31%	36%

**Comfort Revealing HIV Status**

Primary Care Only	46%	46%	50%	57%	36%
Family/Friends	29%	36%	0%	36%	21%
Anyone	<u>25%</u>	<u>18%</u>	<u>50%</u>	<u>7%</u>	<u>43%</u>
	100%	100%	100%	100%	100%

**Table 6: Employment And Financial Assistance Among PLWHA**

<b><u>Employment Status</u></b>	<b>Gender</b>			<b>Care Status</b>	
	<b>Total (N=28)</b>	<b>Male (N=22)</b>	<b>Female (N=6)</b>	<b>HIV (N=14)</b>	<b>AIDS (N=14)</b>
Working full or part time	46%	50%	33%	57%	36%
On SS/Disability, Retired, or dependent minor	25%	14%	67%	14%	36%
Unemployed looking for work or applying for disability	18%	22%	0%	22%	14%
Unemployed not looking for work	11%	14%	0%	7%	14%
	100%	100%	100%	100%	100%
<b><u>Income Assistance</u></b>					
Dependent Child	8% (50)	8% (58)	0% (17)	14% (71)	0% (28)
No Assistance Recieved	42%	50%	17%	57%	28%
HIV/AIDS Drugs Only	18% (18)	25% (25)	0% (0)	22% (22)	14% (14)
SS/Disability Only	17% (32)	4% (17)	17% (83)	0% (7)	14% (58)
Food Stamp Plus Other	14%	9%	33%	7%	22%
Rent Plus Other	11%	4%	33%	0%	22%
	100%	100%	100%	100%	100%
<b><u>How Do You Pay For Medication/Treatment?</u></b>					
Not on medications	14%	18%	0%	14%	14%
Insurance	35%	41%	17%	44%	29%
ADAP	18%	14%	33%	14%	21%
Medicaid/Medicare/MIP	29%	23%	50%	21%	36%
Owe/Not Paid	4%	4%	0%	7%	0%
	100%	100%	100%	100%	100%
<b><u>How Do You Pay For Medical Bills?</u></b>					
Early Stage, No Bills	11%	14%	0%	7%	14%
Insurance	32%	36%	17%	36%	29%
Ryan White CARE ACT	7%	5%	17%	7%	7%
Medicaid/Medicare/MIP	32%	23%	66%	21%	43%
Self/Family	11%	14%	0%	14%	7%
Owe/Not Paid	7%	8%	0%	14%	0%
	100%	100%	100%	100%	100%



**Table 7: Assessment Of Monthly Income And Budgetary Expenses For Those With  
Income And Reporting Data Information**

		<b>Gender</b>		<b>Care Status</b>	
	<u><b>Total</b></u>	<u><b>Male</b></u>	<u><b>Female</b></u>	<u><b>HIV</b></u>	<u><b>AIDS</b></u>
<b>No Assistance/Welfare</b>		(M=7)		(N=5)	(N=2)
Monthly Income (Gross)		1,879.14		1,729.00	2,267.00
Sum of Expenses		603.33		661.75	643.45
Sum as % of Income		32%		38%	28%
Rent/Mortgage		323.14		392.40	150.00
Utilities		104.29		146.00	156.95
Health Care		114.43		77.00	208.00
Medications		49.50		10.00	128.50
<b>On Assistance/Welfare</b>	(N=10)	(N=5)	(N=5)	(N=2)	(N=8)
Monthly Income (Gross)	1,530.20	1,710.40	1,350.00	925.00	1,681.50
Sum of Expenses	1,279.40	1,505.60	1,053.20	594.50	1,450.62
Sum as % of Income	84%	88%	78%	64%	86%
Rent/Mortgage	366.00	300.00	432.00	275.00	388.75
Utilities	205.40	169.60	241.20	134.50	223.13
Health Care	504.00	708.00	300.00	60.00	615.00
Medications	246.00	342.00	150.00	125.00	276.25
<b>No Assistance/Welfare</b>		(N=7)		(N=5)	(N=2)
<u>Medication Coverage</u>					
Insurance		6		4	2
ADAP		1		1	0
<u>Medical Bills</u>					
Insurance		5		3	2
Ryan White		1		1	0
Self/Family		1		1	0
<b>On Assistance/Welfare</b>	(N=10)	(N=5)	(N=5)	(N=2)	(N=8)
<u>Medication Coverage</u>					
Insurance	2	2	0	1	1
ADAP	3	1	2	0	3
MIP/Medicaid	5	2	3	1	4
<u>Medical Bills</u>					
Insurance	2	2	0	1	1
Ryan White	1	0	1	0	1
MIP/Medicaid	6	2	4	1	5
Self/Family	1	0	1	0	1

**Table 8: Housing and Residence Traits, Preferences And Experiences Among PLWHA**

	Gender			Care Status	
	<u>Total</u> (N=28)	<u>Male</u> (N=22)	<u>Female</u> (N=6)	<u>HIV</u> (N=14)	<u>AIDS</u> (N=14)
<b>Current Household</b>					
Own House, Condo Or Rent Apartment	53	45	83	43	65
Rent Room/Space In A House	11	9	17	0	21
Stay For Free Friends/ Family	28	36	0	43	14
Correctional Facility	4	5	0	7	0
Homeless	<u>4</u>	<u>5</u>	<u>0</u>	<u>7</u>	<u>0</u>
	100%	100%	100%	100%	100%
<b><u>Transitional Housing Preferences</u></b>					
1a. Prefer Family Or Friends	70	71	67	70	69
1b. Share Housing With Other PLWHA	<u>30</u>	<u>29</u>	<u>33</u>	<u>30</u>	<u>31</u>
	100%	100%	100%	100%	100%
2a. Building With Daily Services	26	14	60	33	20
2b. Services External or Separate of Housing	<u>74</u>	<u>86</u>	<u>40</u>	<u>67</u>	<u>80</u>
	100%	100%	100%	100%	100%
	Gender			Care Status	
	<u>Total</u> (N=28)	<u>Male</u> (N=22)	<u>Female</u> (N=6)	<u>HIV</u> (N=14)	<u>AIDS</u> (N=14)
<b><u>Ever Homeless</u></b>					
Yes	29% (8)	32% (7)	17% (1)	29% (4)	29% (4)
<b><u>In Past 3 Years How Long homeless</u></b>					
Less than 1 week	14% (4)	14%	17%	8%	21%
More than 1 week	14% (4)	18%	0%	21%	8%
<b><u>Ever Feel Discrimination Trying To Get Housing</u></b>					
No	82%	76%	100%	93v	82%
Yes – My HIV/AIDS	4%	4%		0%	4%
Yes – My disability	7%	10%		0%	7%
Yes - Other	<u>7%</u>	<u>10%</u>		<u>7%</u>	<u>7%</u>
	100%	100%		100%	100%
<b><u>Other Difficulty Getting Housing</u></b>					
No	81%	76%	100%	86%	79%
Substance Abuse	4%	5%		7%	0%
Bad Credit	4%	5%		7%	0%
Nothing Affordable	7%	9%		0%	14%
Transportation/Location	4%	5%		0%	7%
	<u>100%</u>	<u>100%</u>	<u>100%</u>	<u>100%</u>	<u>100%</u>

**Table 9: Perceived Availability On Guam And Attempted Access Of Psycho-Social  
Need Services (In Rank Order): Percent Responding YES**

		Gender		Care Status	
	Total	Male	Female	HIV	AIDS
	(N=28)	(N=22)	(N=6)	(N=14)	(N=14)
<b><u>Support Group Counseling</u></b>					
Perceived Availability	32%	32%	33%	29%	36%
Attempted Access	25%	18%	67%	21%	42%
<b><u>Emotional/Practical Counseling</u></b>					
Perceived Availability	18%	9%	50%	29%	7%
Attempted Access	22%	19%	33%	21%	23%
<b><u>Individual Counseling</u></b>					
Perceived Availability	61%	58%	67%	62%	58%
Attempted Access	28%	20%	50%	14%	46%
<b><u>Family Counseling</u></b>					
Perceived Availability	40%	37%	50%	54%	25%
Attempted Access	23%	15%	50%	14%	36%
<b><u>Couple Counseling</u></b>					
Perceived Availability	43%	36%	50%	57%	28%
Attempted Access	25%	25%	33%	21%	21%
<b><u>Substance Abuse</u></b>					
Perceived Availability	61%	60%	67%	77%	46%
Attempted Access	15%	14%	17%	21%	7%

Note: If "Perceived Availability" is less than "Attempted Access," then more people tried to get that service than see it as being available (1 or 2 in these data).

**Table 10: Perceived Availability On Guam And Attempted Access Of Case Management Services (In Rank Order): Percent Responding YES**

		<b>Gender</b>		<b>Care Status</b>	
	<b>Total</b>	<b>Male</b>	<b>Female</b>	<b>HIV</b>	<b>AIDS</b>
	(N=27)	(N=21)	(N=6)	(N=13)	(N=14)
<b><u>Service Coordination</u></b>					
Perceived Availability	59%	57%	67%	54%	64%
Attempted Access	52%	52%	50%	46%	57%
<b><u>Treatment Advocacy</u></b>					
Perceived Availability	48%	52%	33%	54%	43%
Attempted Access	41%	38%	50%	46%	36%
<b><u>Information and Referral</u></b>					
Perceived Availability	74%	76%	67%	76%	71%
Attempted Access	67%	67%	67%	69%	64%
<b><u>Legal Services</u></b>					
Perceived Availability	29%	23%	50%	36%	21%
Attempted Access	14%	14%	17%	14%	14%

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Note: If "Perceived Availability" is less than "Attempted Access," then more people tried to get that service than see it as being available (1 or 2 in these data).



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 p p p p

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4/7/04

Chart 2a: Year Learned of Status and Current Age Among PLWHA Who Responded

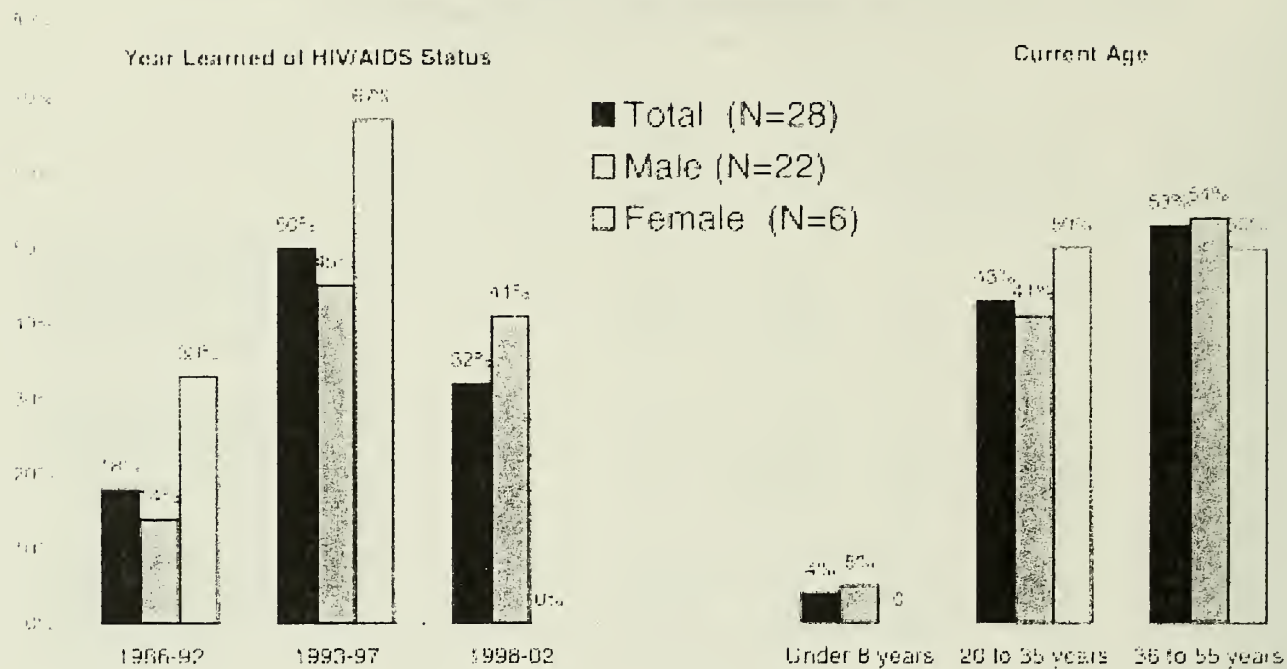


Chart 2b: Care Status by Gender Of PLWHA Who Responded To The Survey

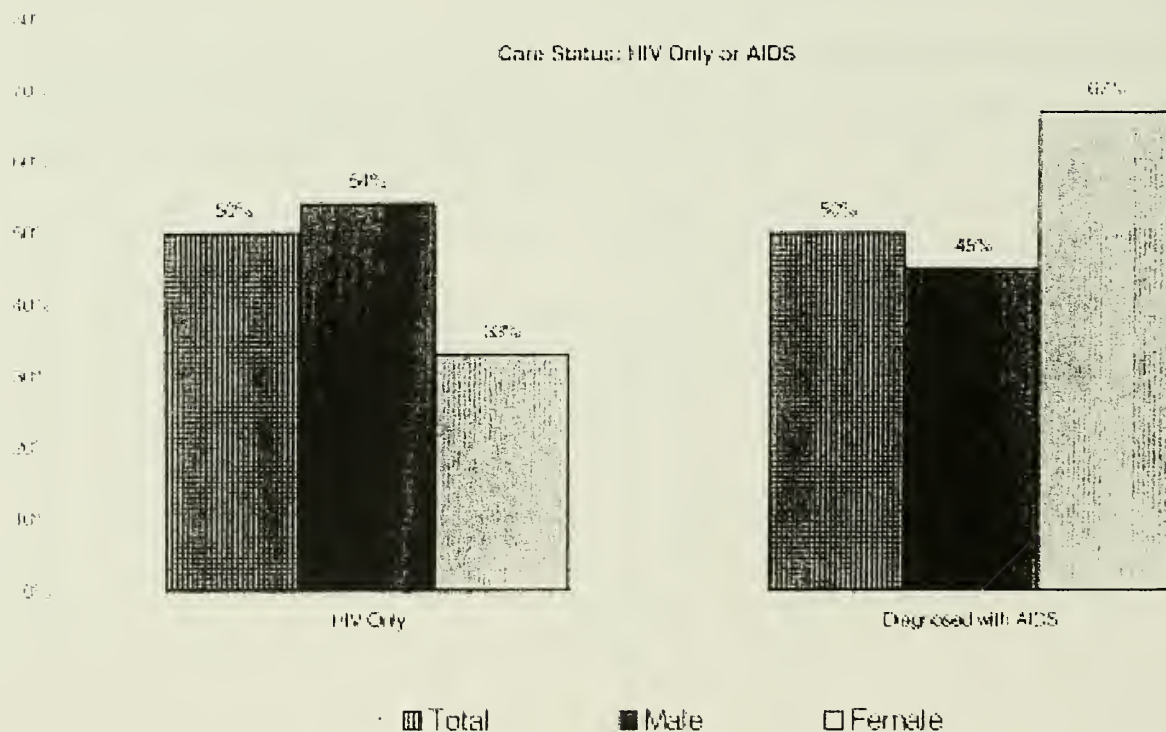


Chart 26. Ethnicity by Gender of PLWHA Who Responded To The Survey

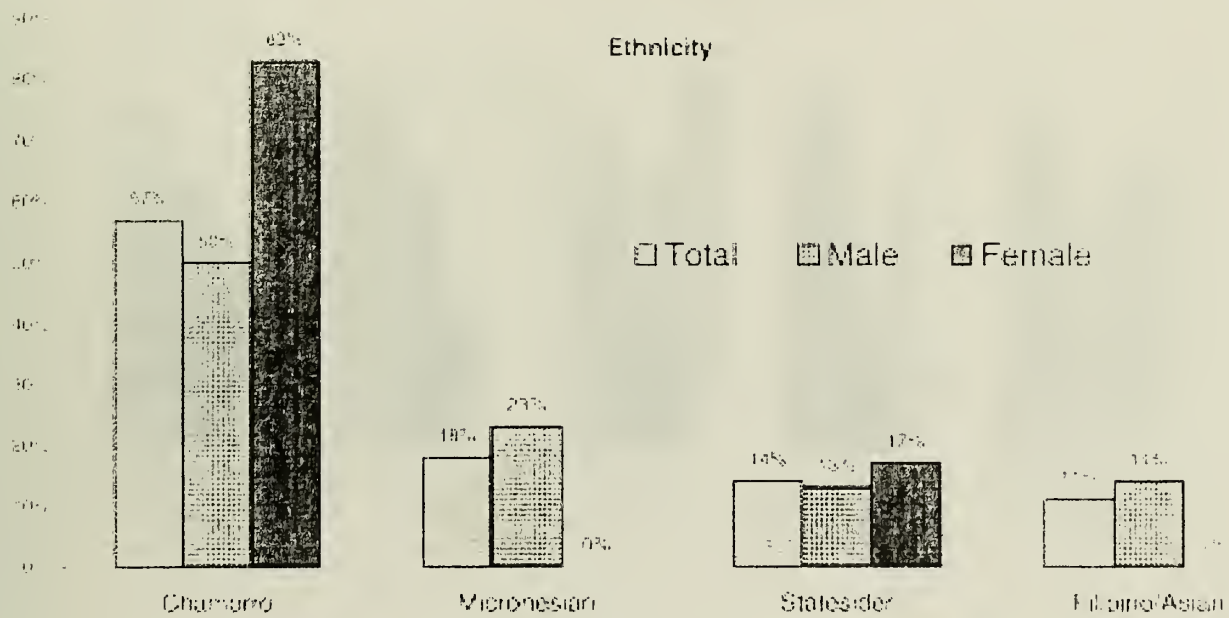


Chart 27. Primary Care On Guam

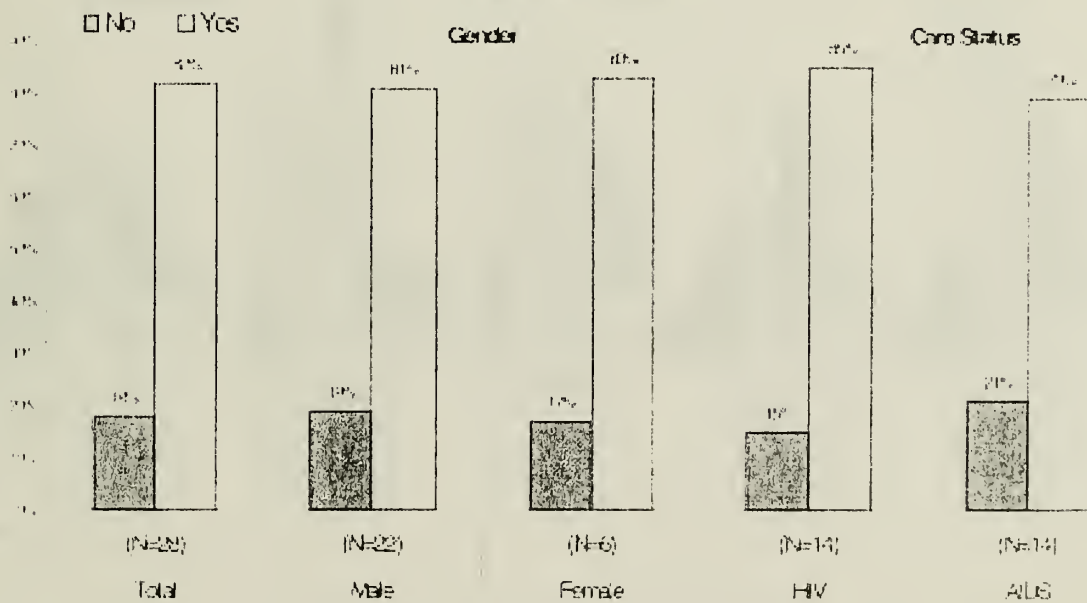


Chart III - Health Services Provider

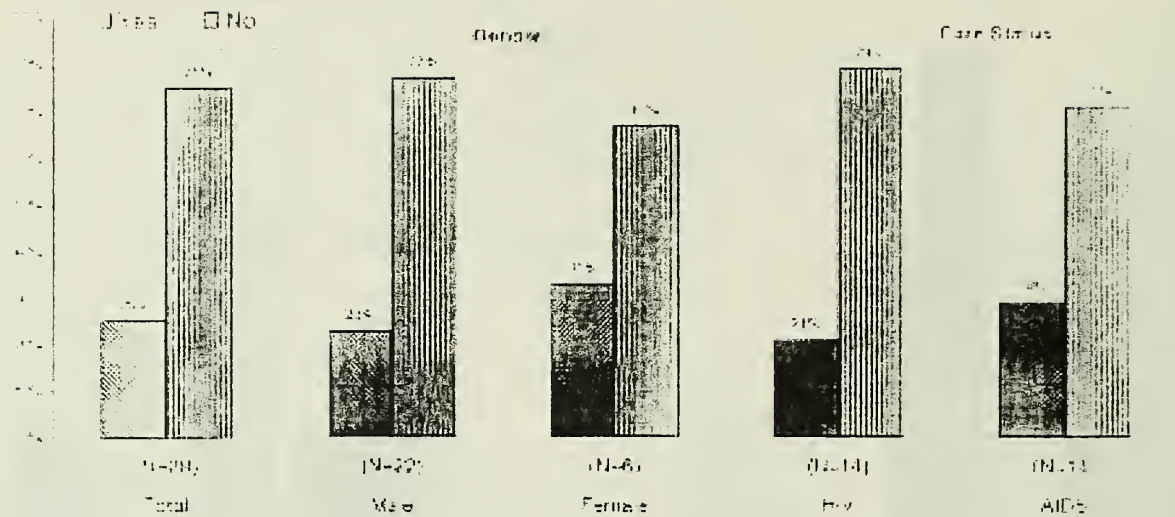


Chart IV - Where Do you Access Care

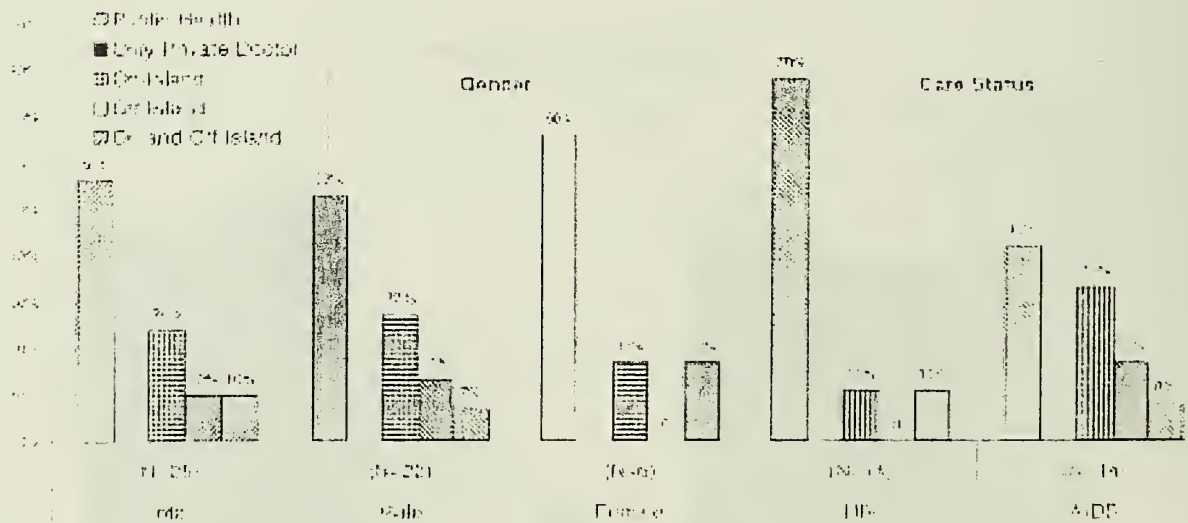




Chart 3d: Number out of 5 Agencies Ever Used

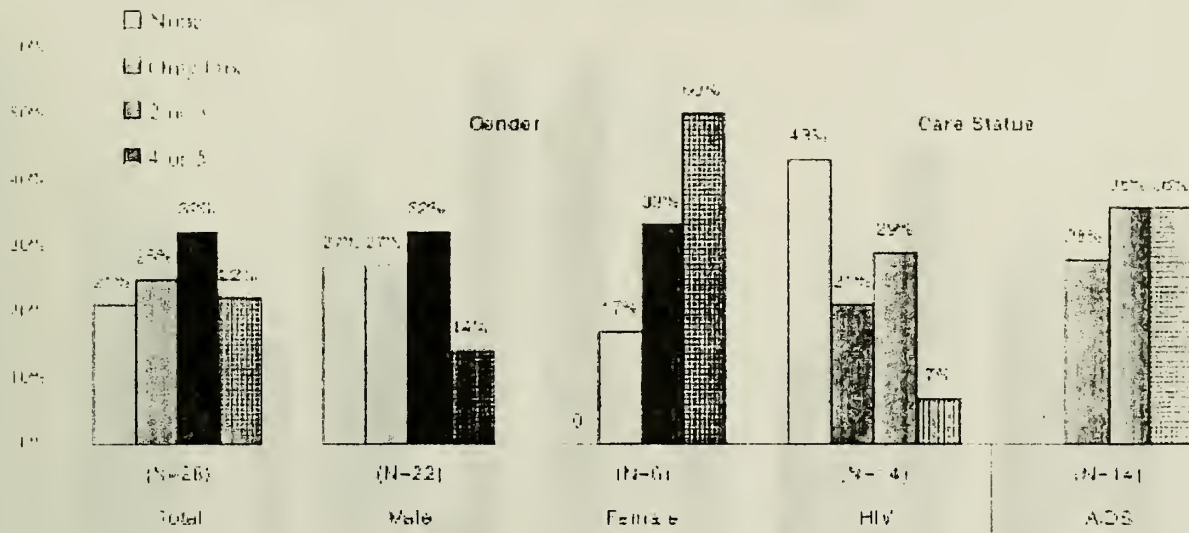


Chart 3e: Percent Ever Used For Service

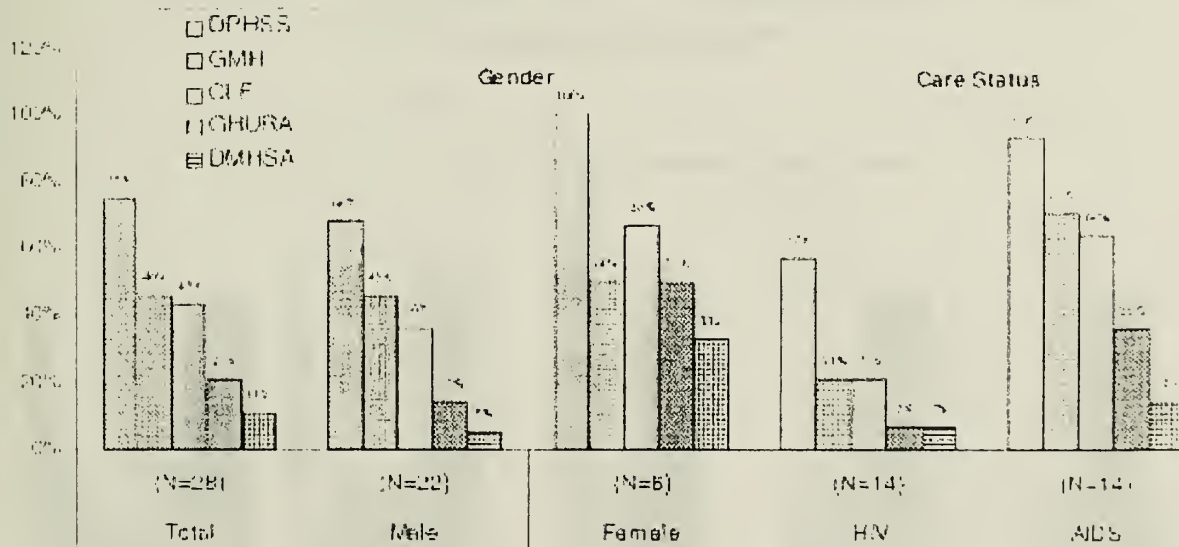


Chart 5a: Problem With Specialist Referral

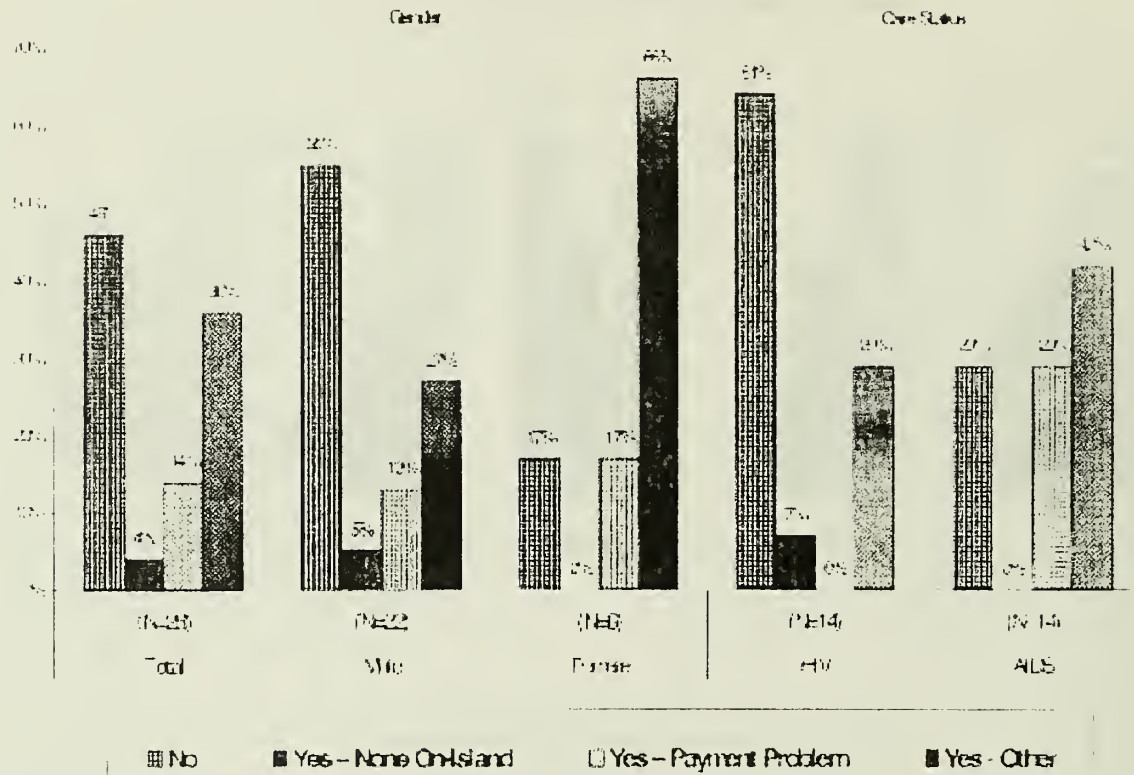


Chart 5b: Problem Communicating With Service Providers

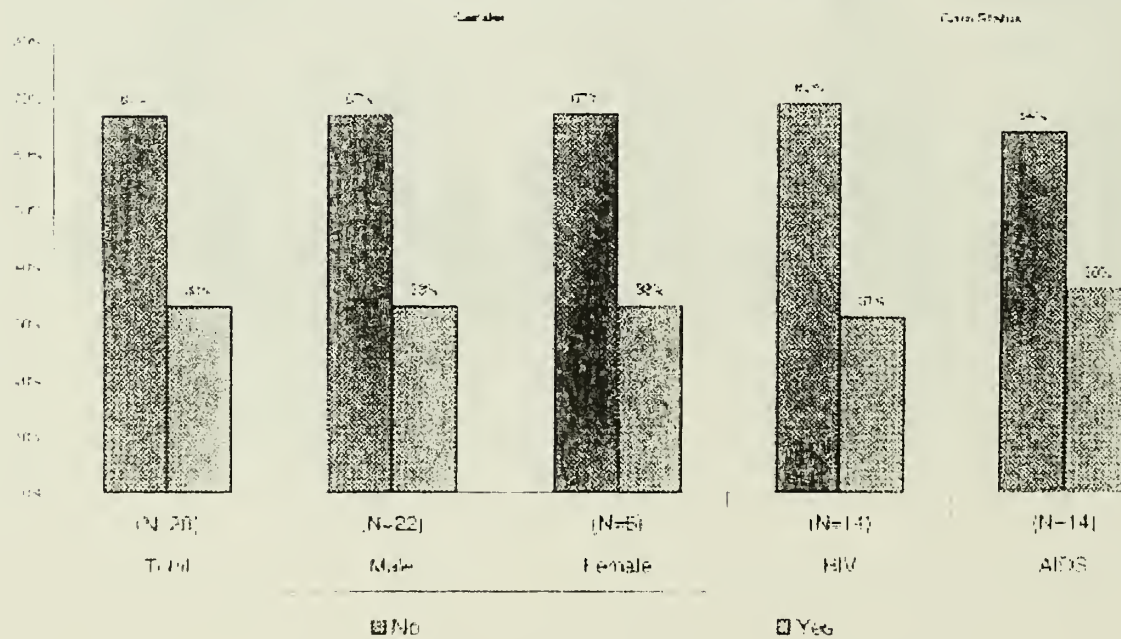


Chart 5a: Comfort Revealing HIV Status

Gender

Care Status

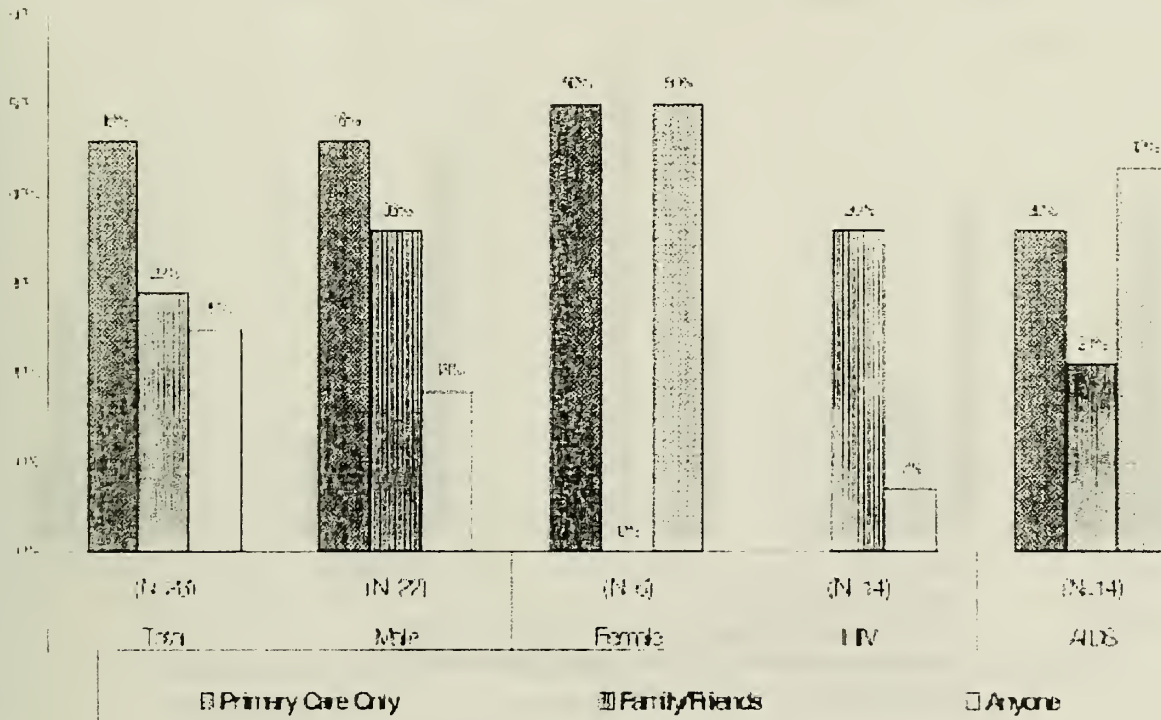


Chart 5a: Employment Status Among PLWHA

Gender

Care Status

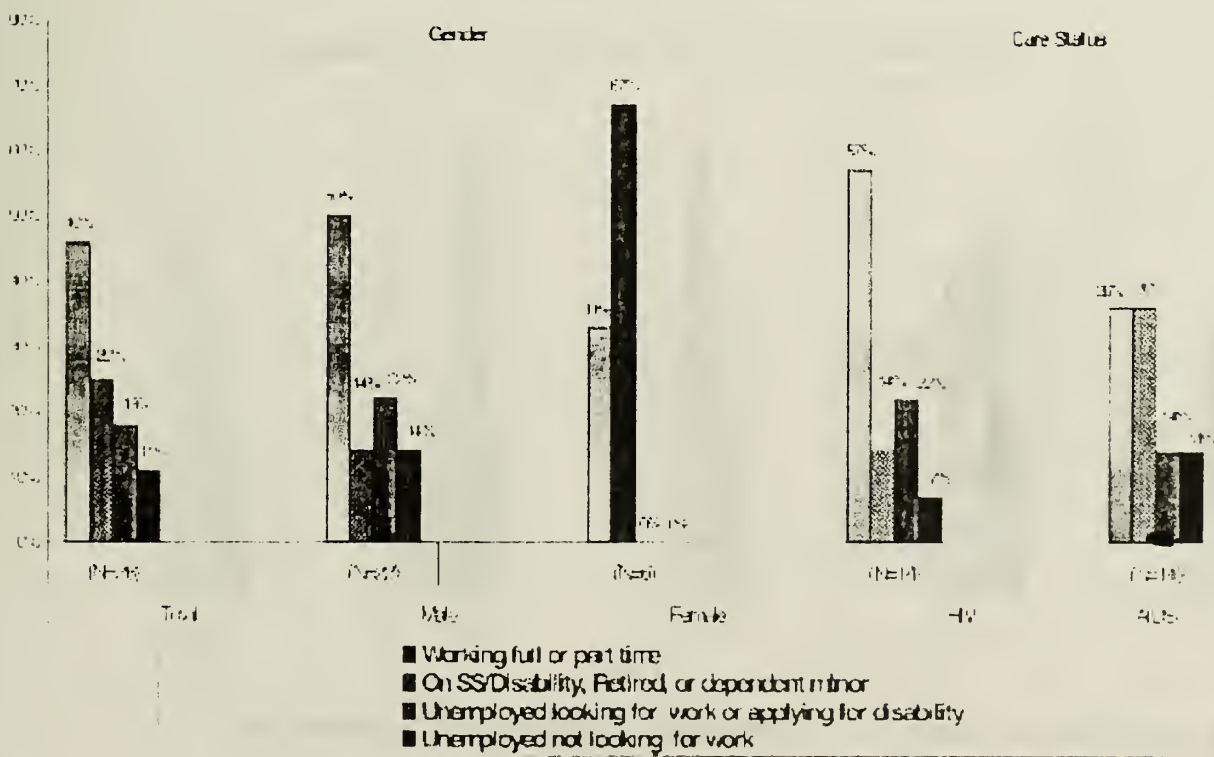




Chart 6a: Income Assistance Among PLWHA

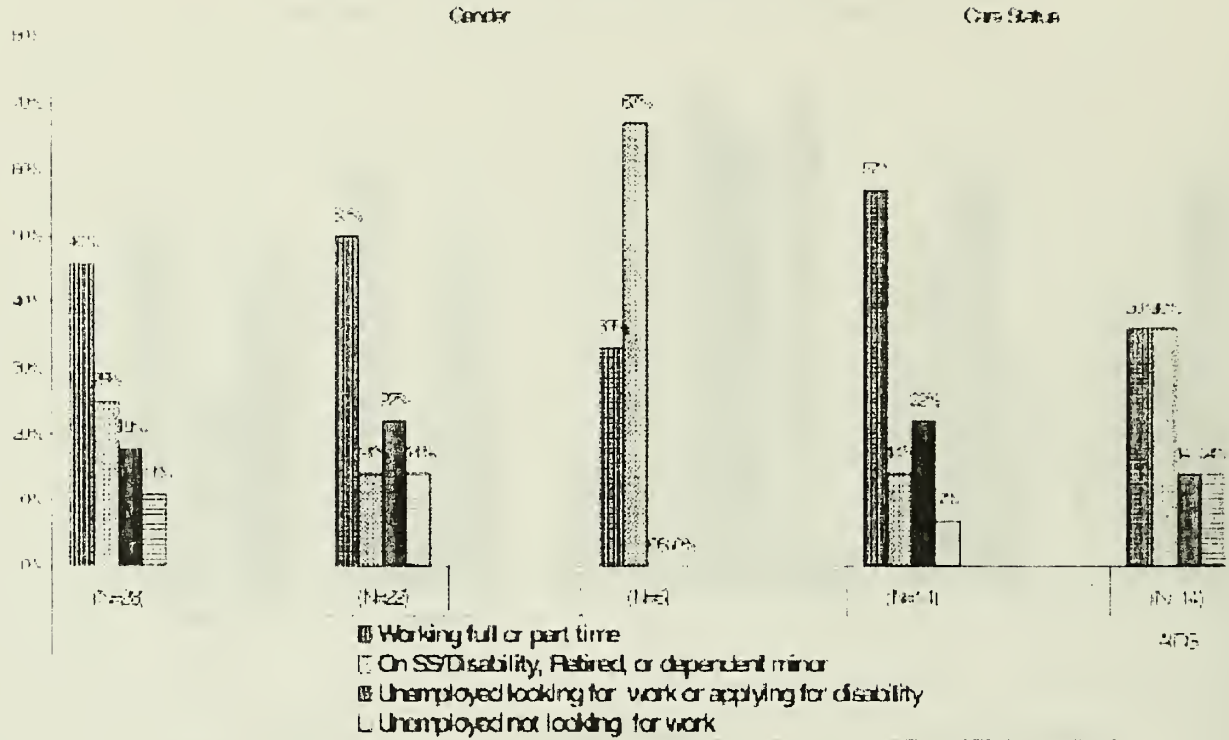


Chart 6c: How Do You Pay For Medication/Treatment?

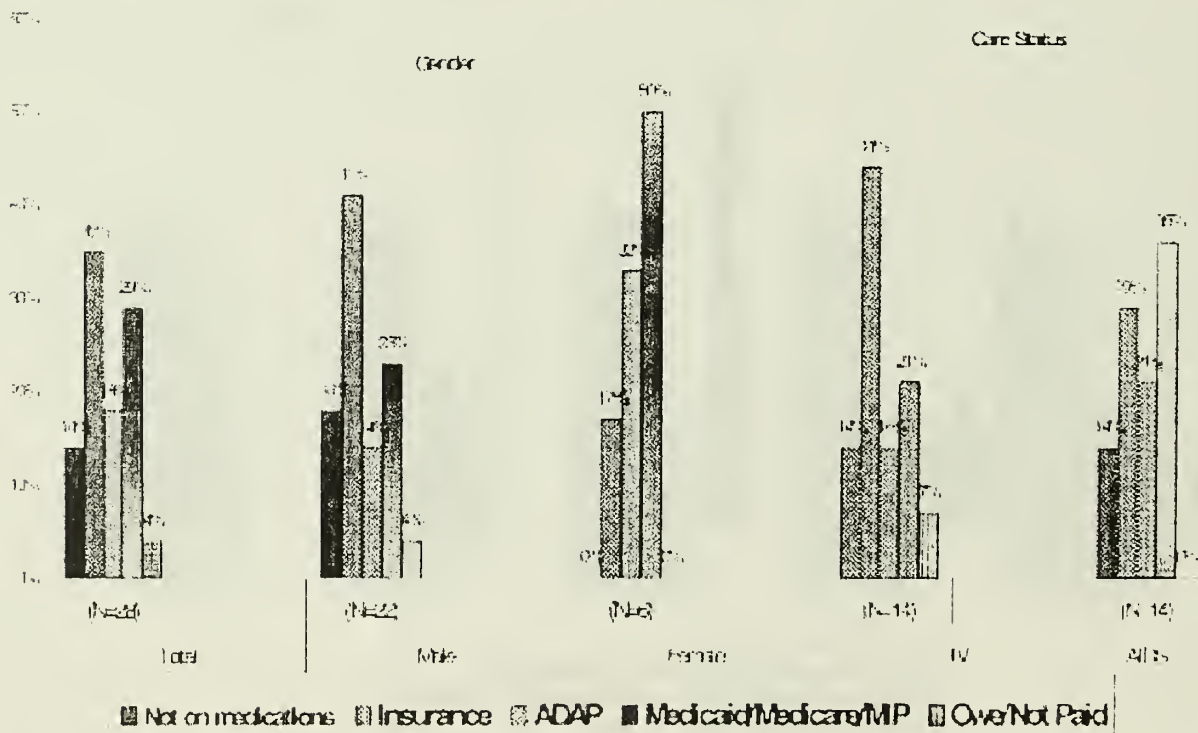




Chart 6d: How Do You Pay For Medical Bills?

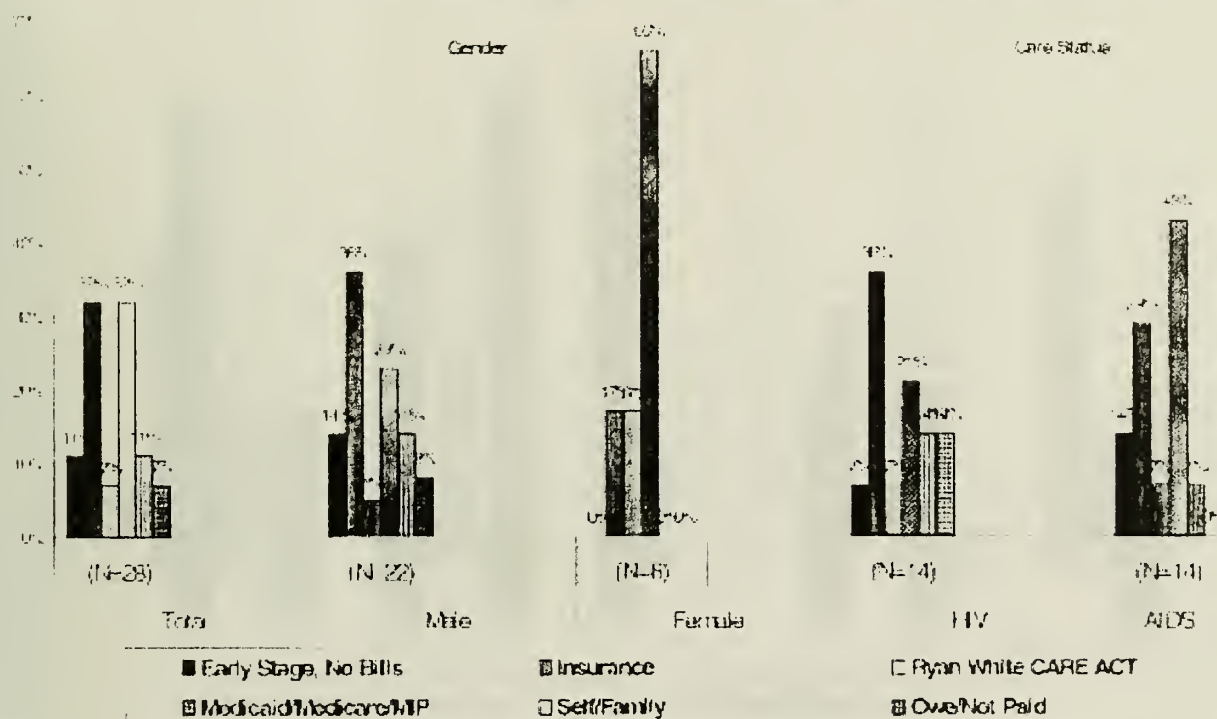
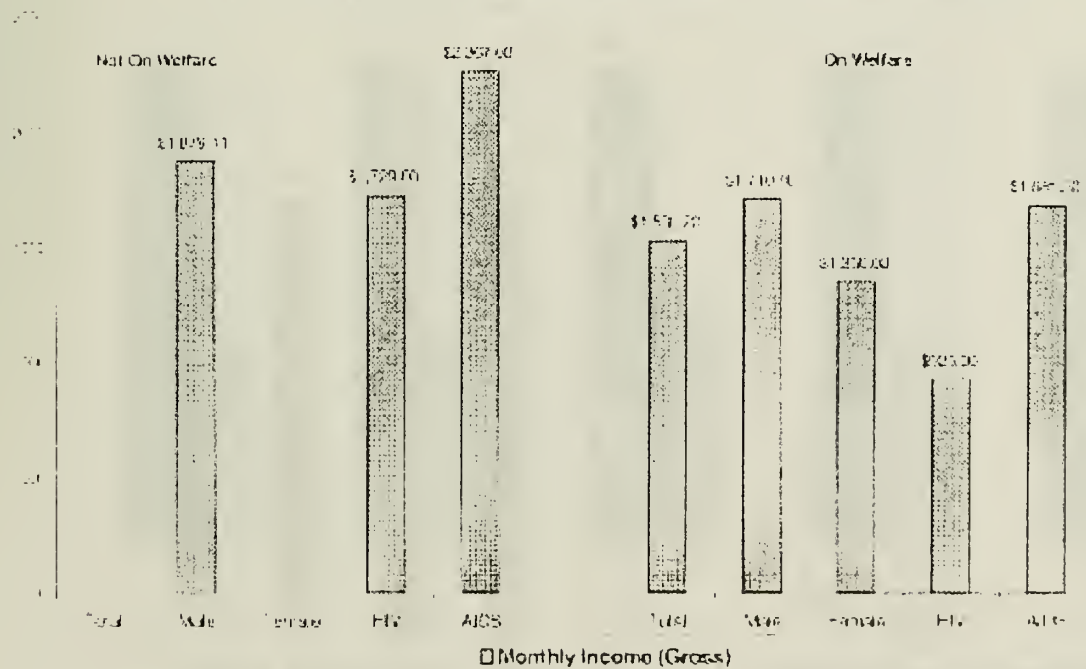
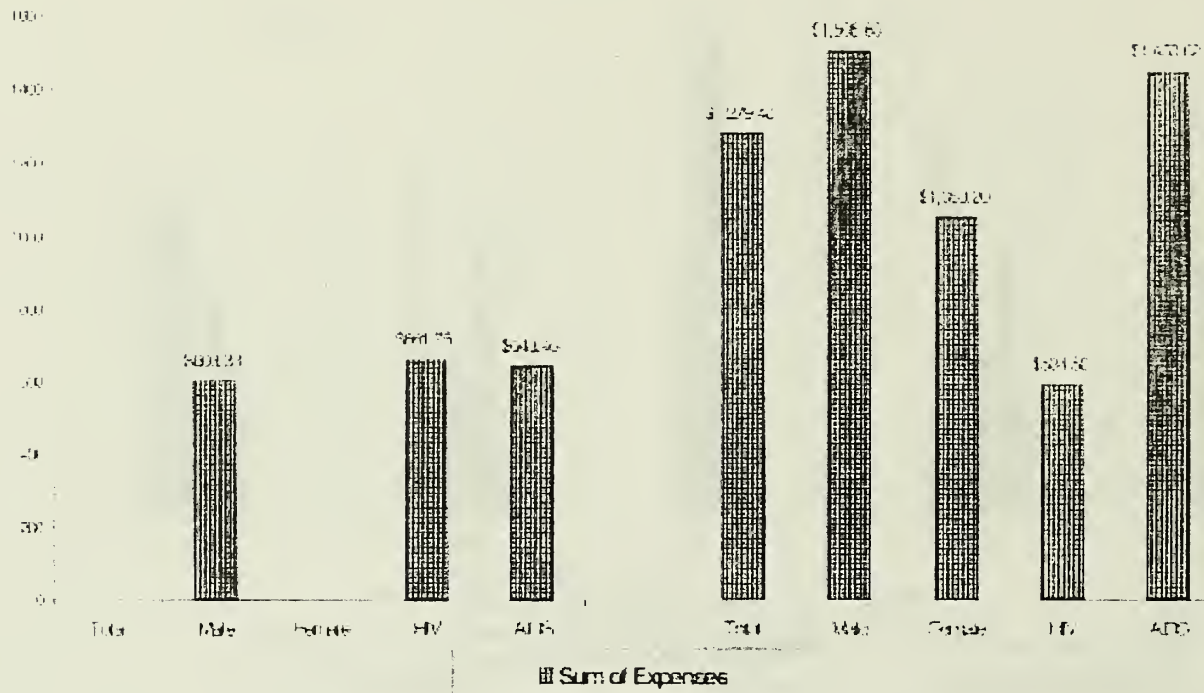


Chart 7a: Average Monthly Income By Gender & Care Status For Those With Income Reporting Data



7a. Average Sum of Expenses By Gender & Care Status For Those Income Reporting Data



7a. Average Expenses as % of Income By Gender & Care Status For Those With Income Reporting Data

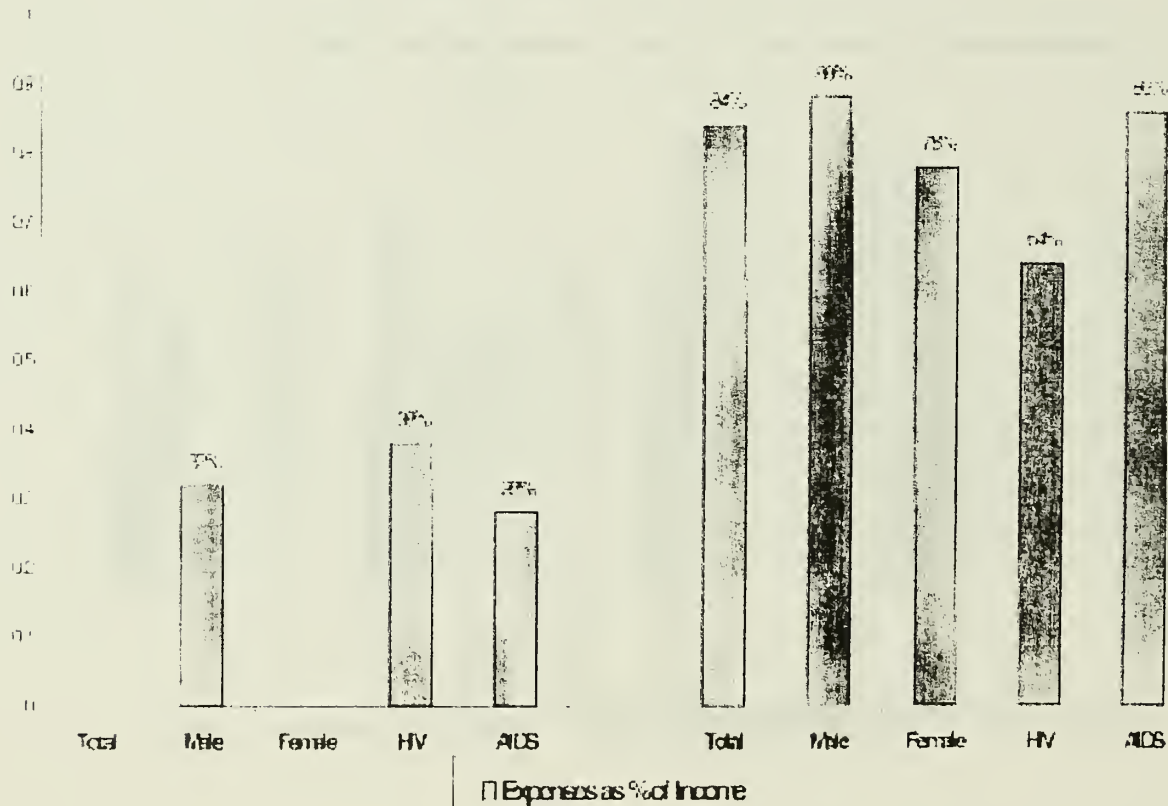


Chart 8a: Current Household Among PLWHA

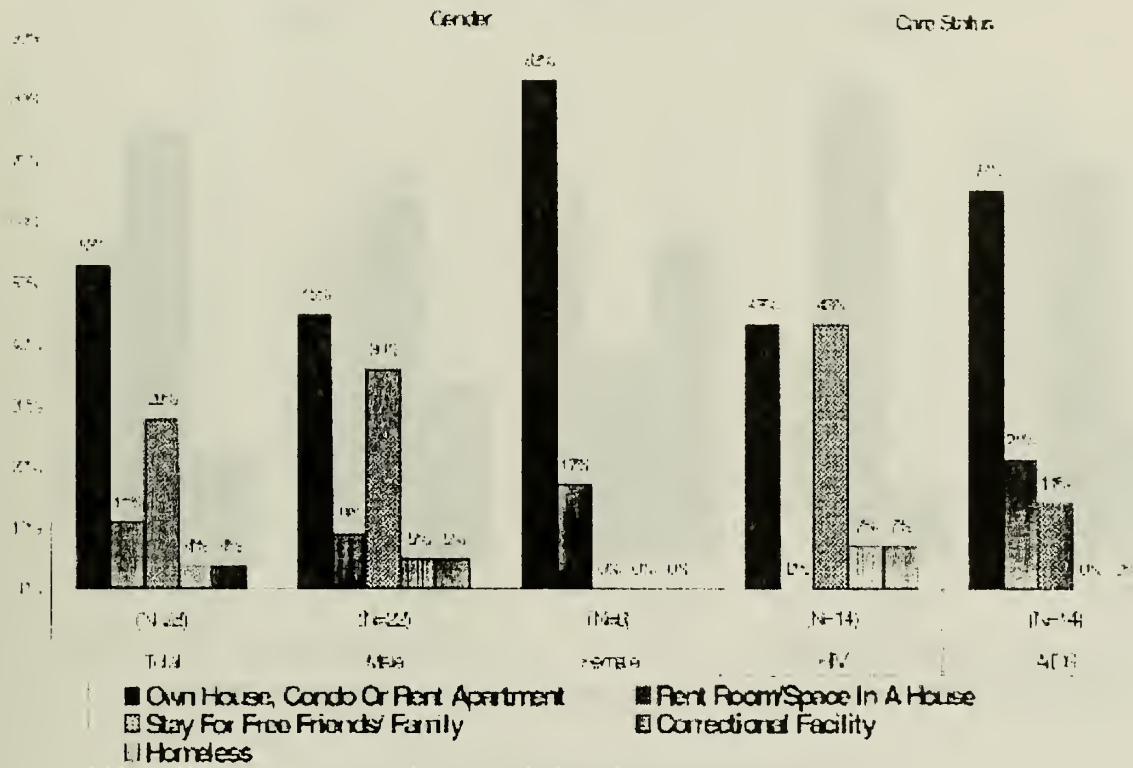


Chart 8b: Transitional Housing Preferences

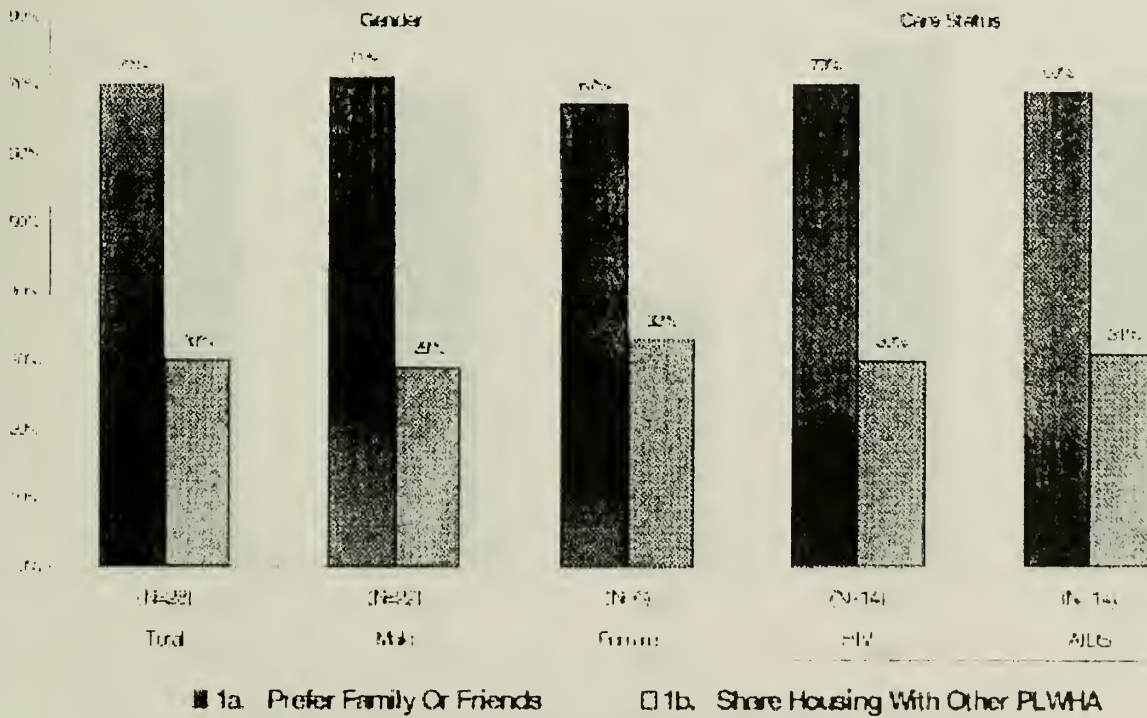




Chart 8b2: Transitional Housing Preferences

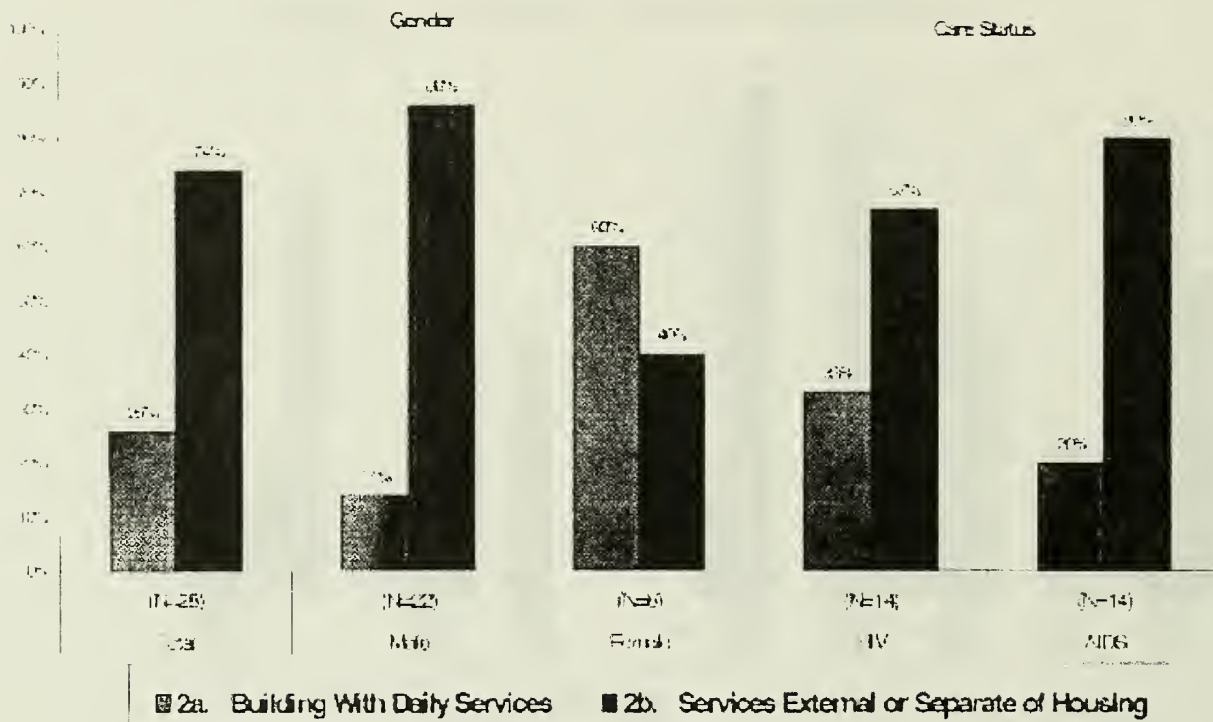


Chart 8c1: Exit Homes

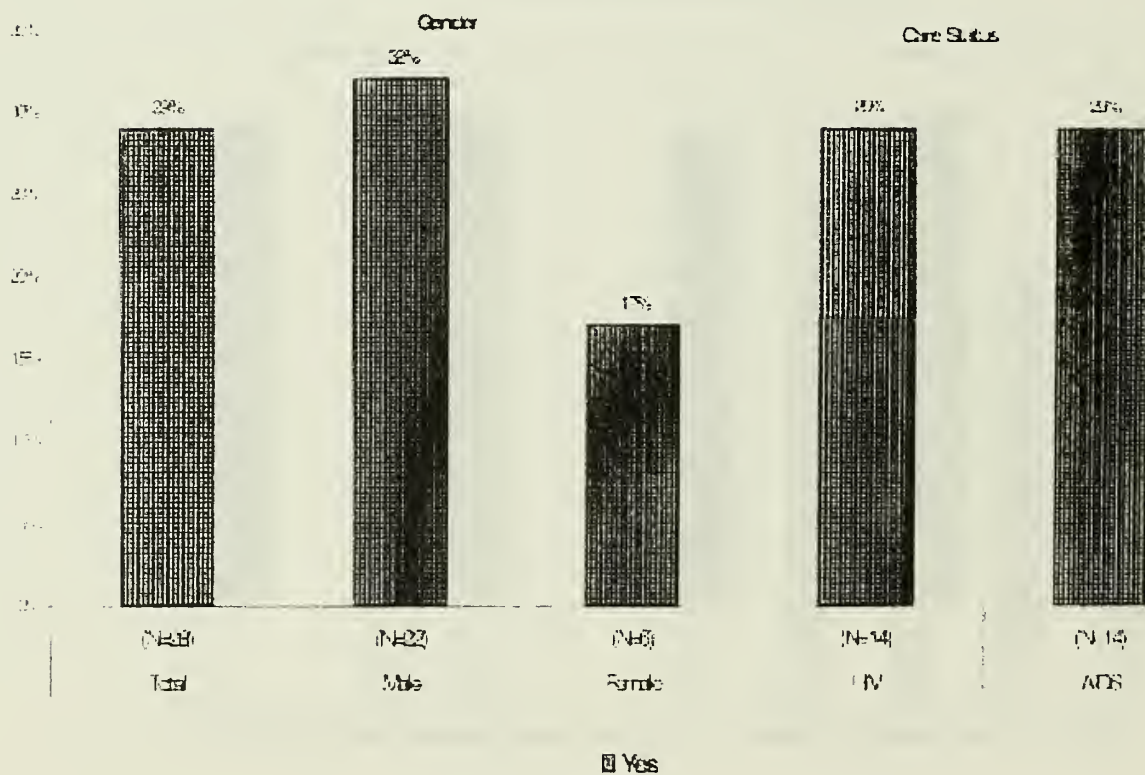




Chart 8c2: In Past 3 Years How Long Homeless

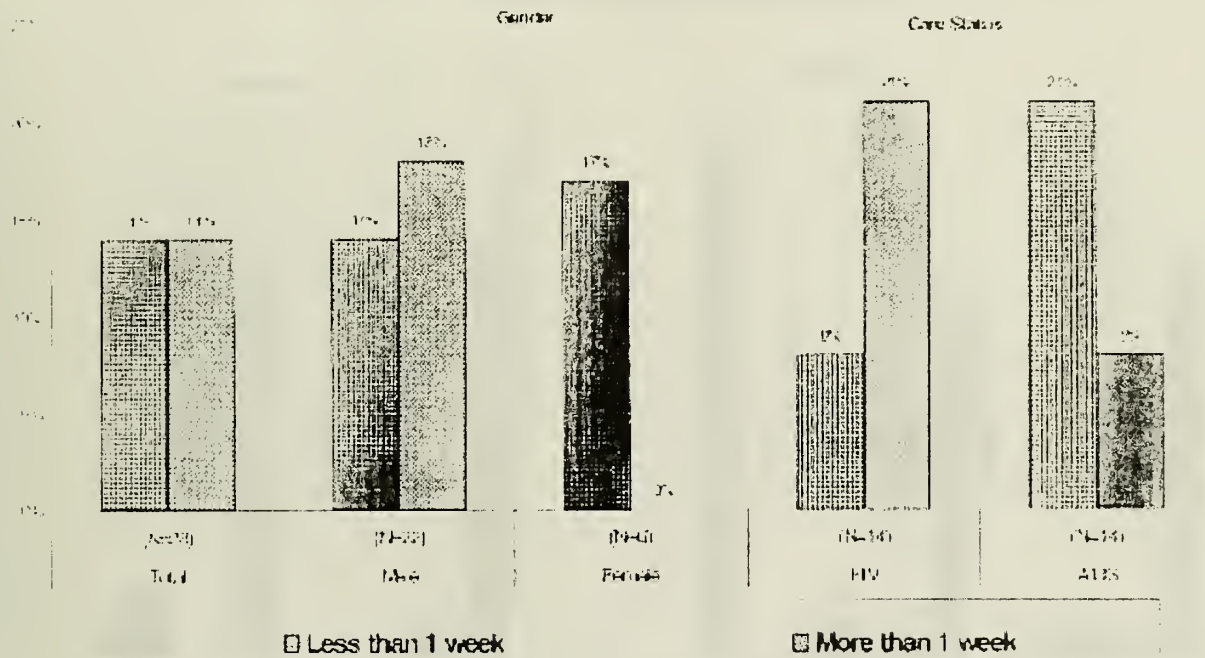


Chart 8d1: Ever Felt Discrimination Trying To Get Housing

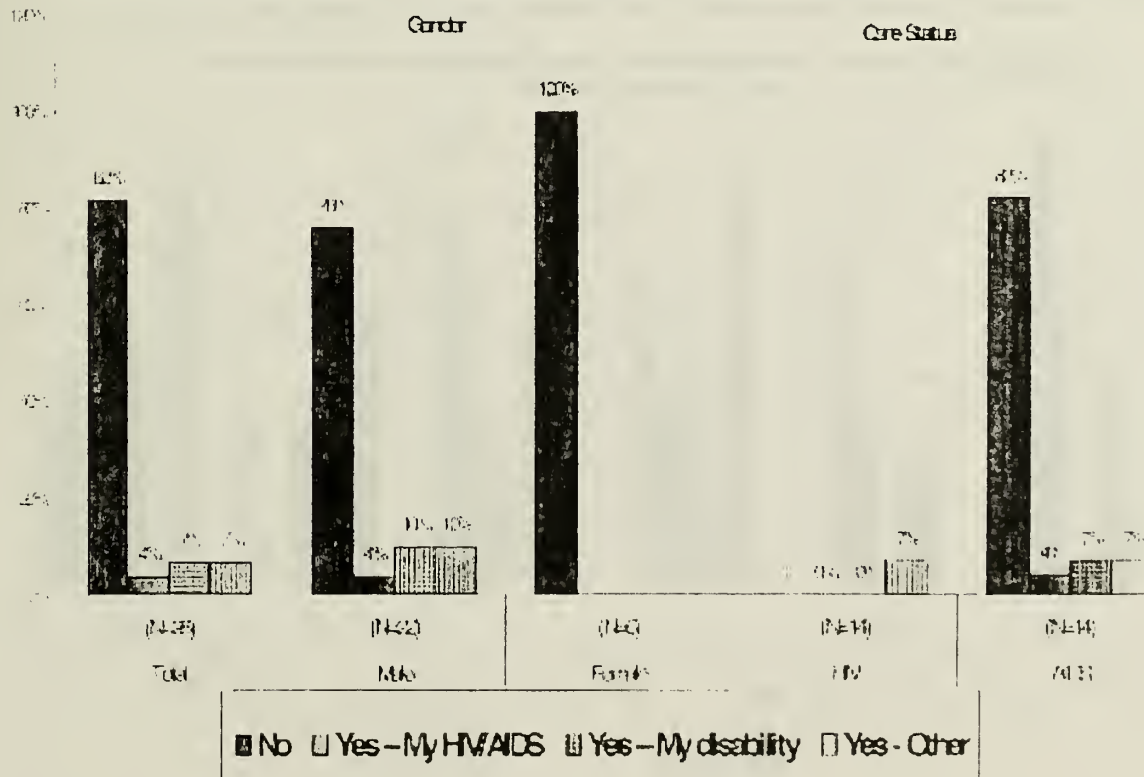


Chart 8c2: Other Difficulty Getting Housing

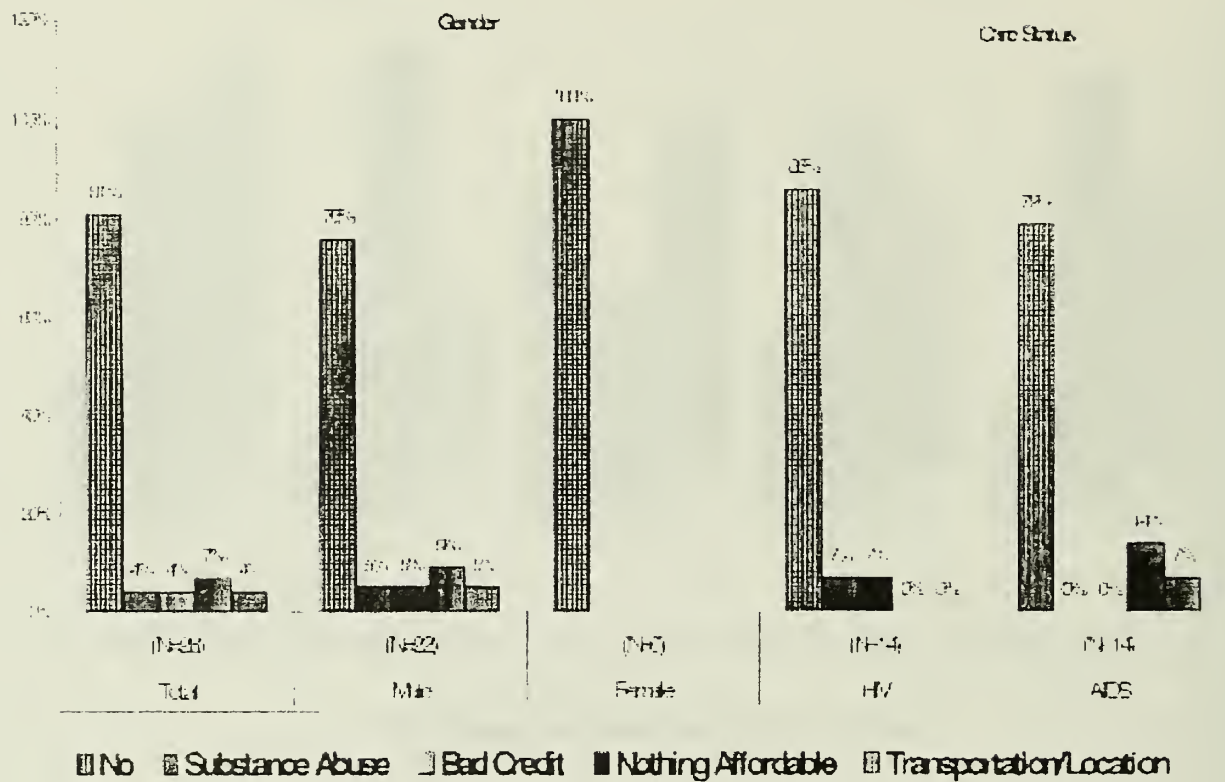


Chart 8a: Perceived Availability on Guam and Attempted Access of Psycho-Social Need Services (in rank order). Percent Responding YES

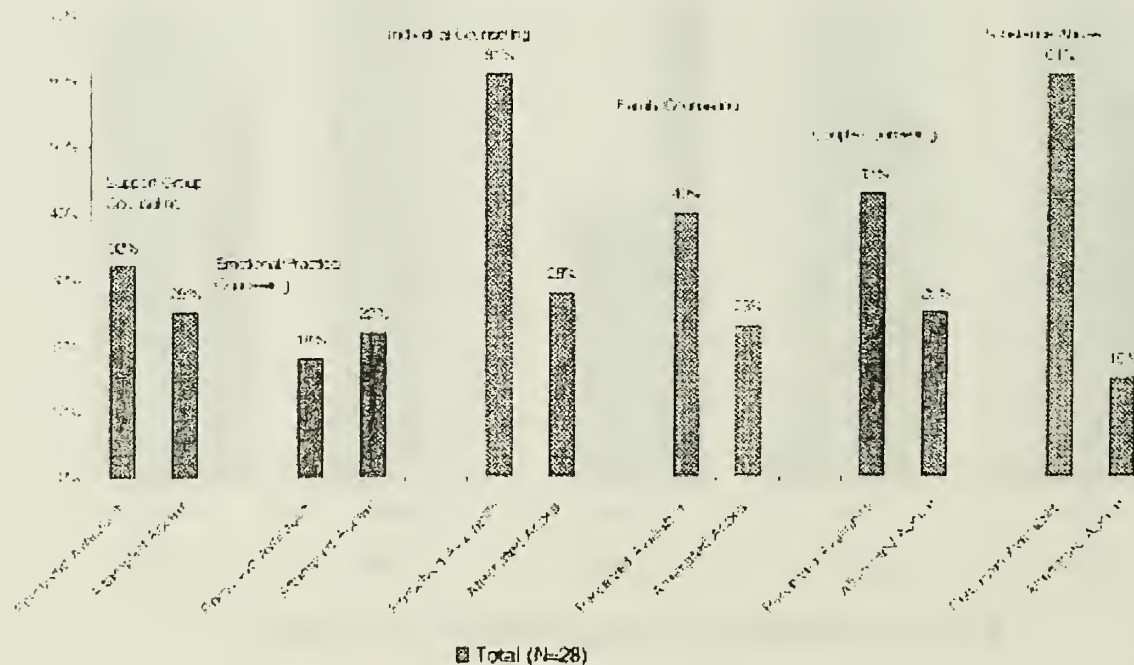


Chart 9a: Perceived Availability on Guam and Attempted Access of Psycho-Social Need Services, By Gender

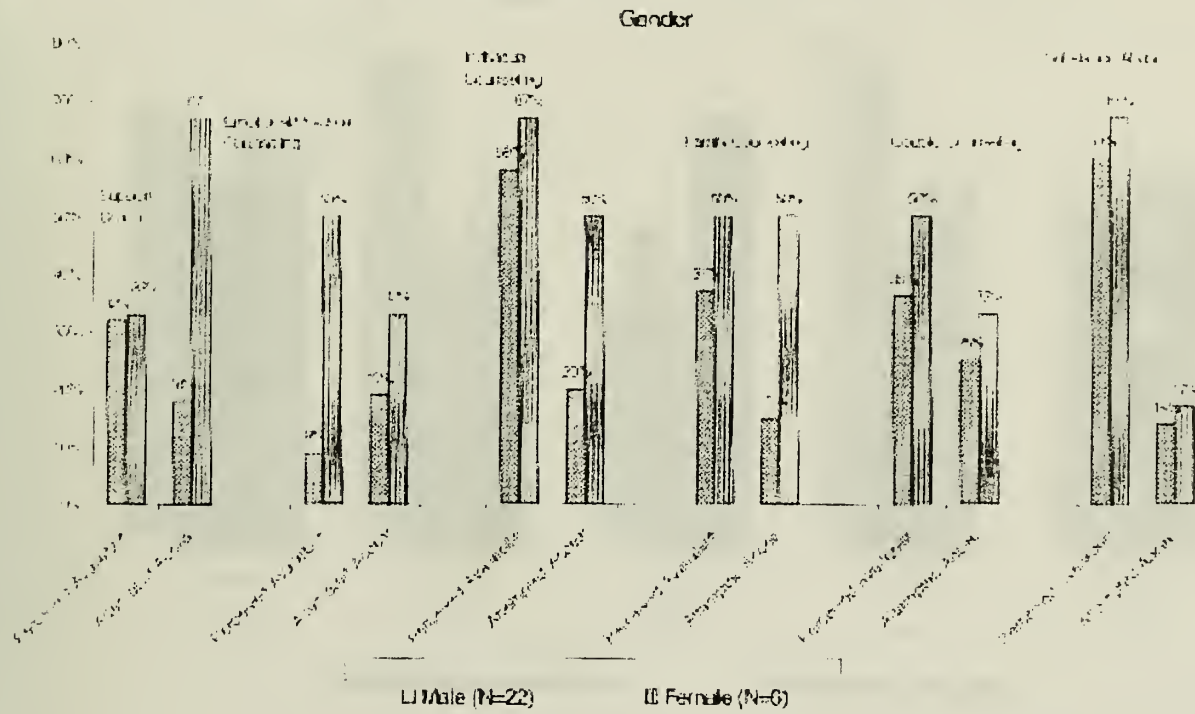


Chart 9a: Perceived Availability on Guam and Attempted Access of Psycho-social Need Services, By Care Status

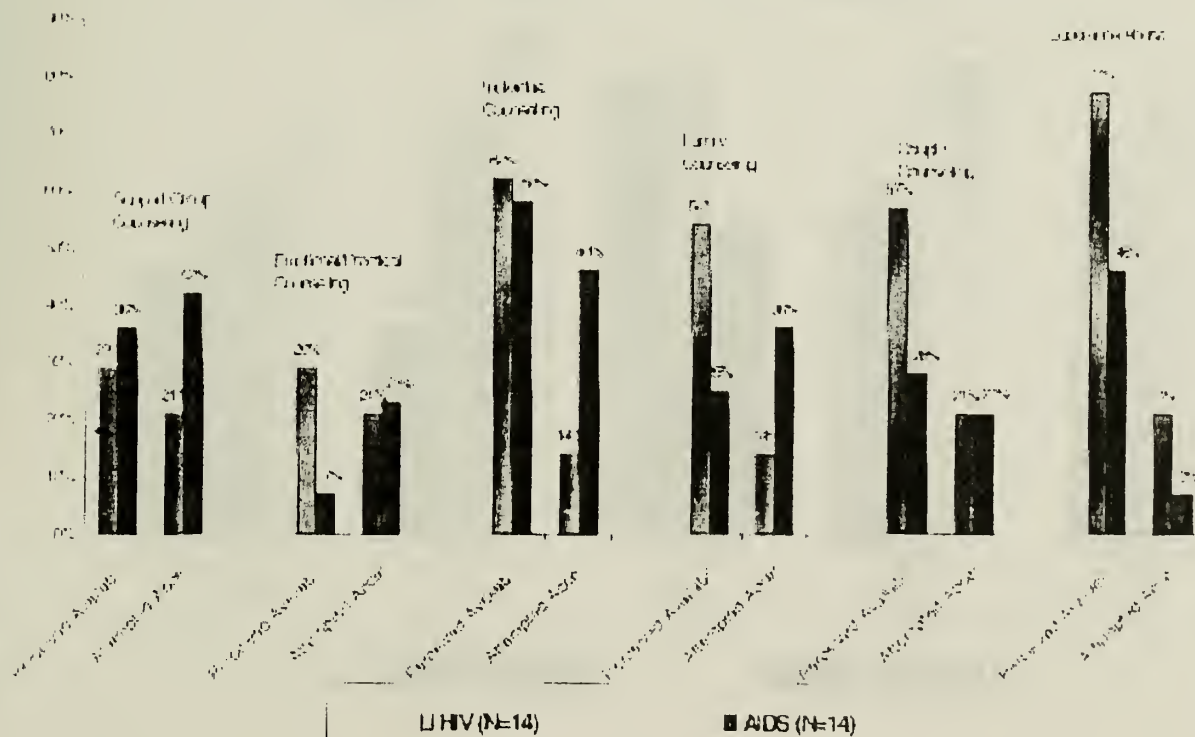




Chart 10a: Service Coordination

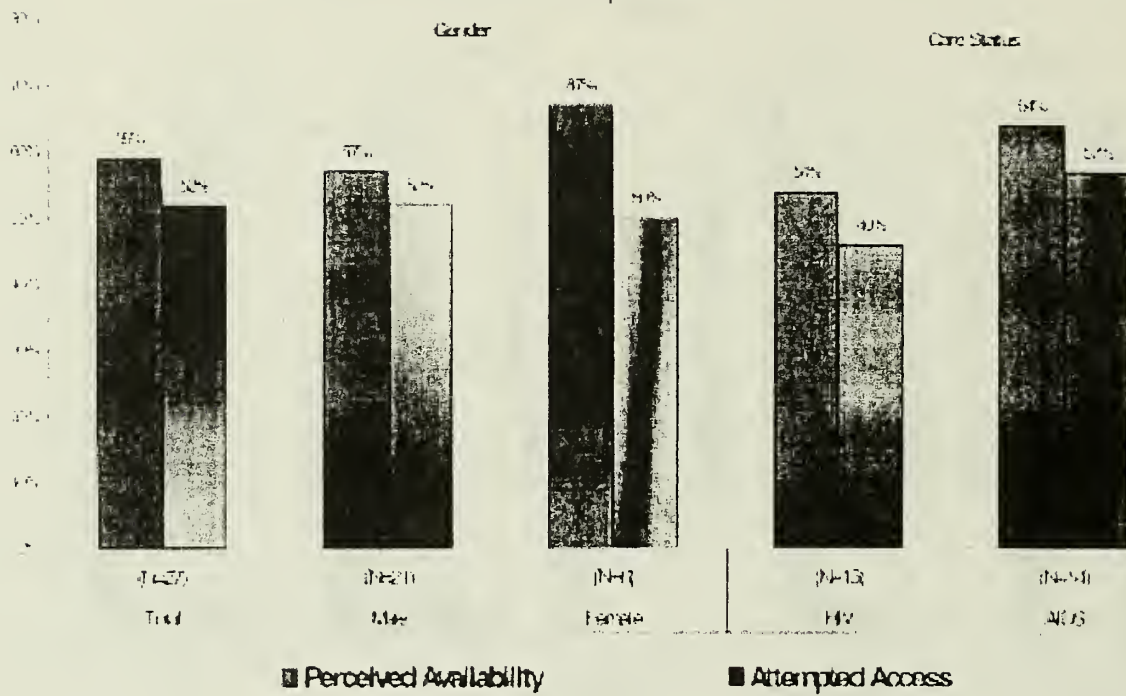


Chart 10b: Treatment Advocacy

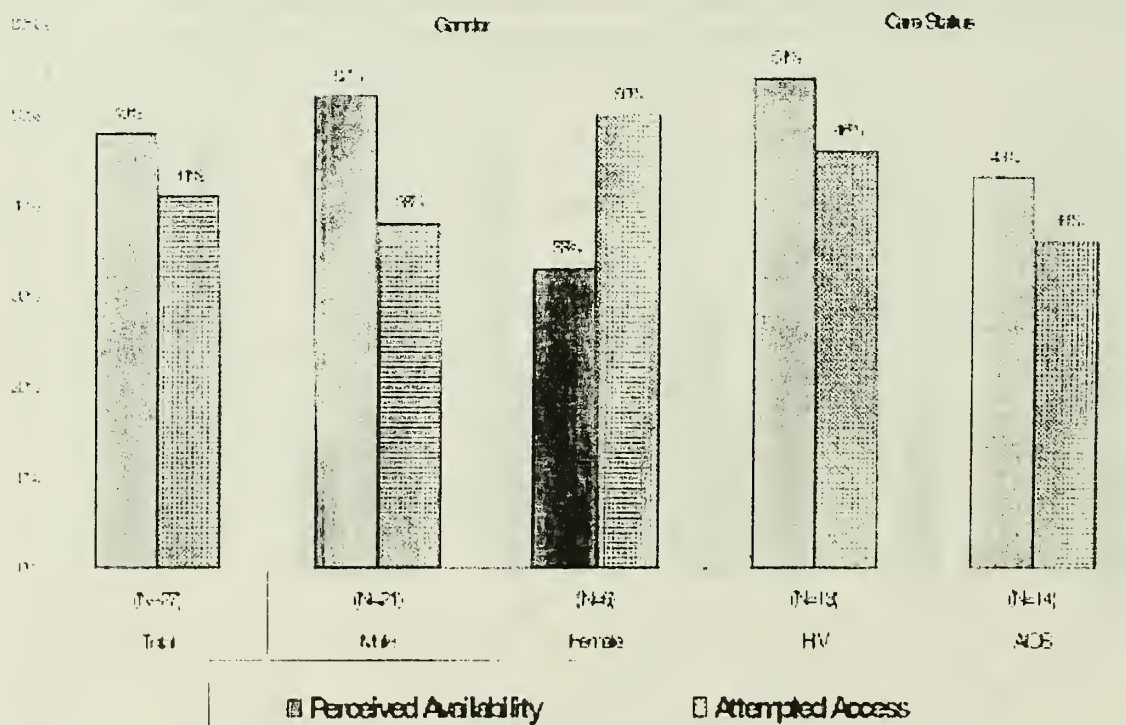




Chart 10c: Information and Referral

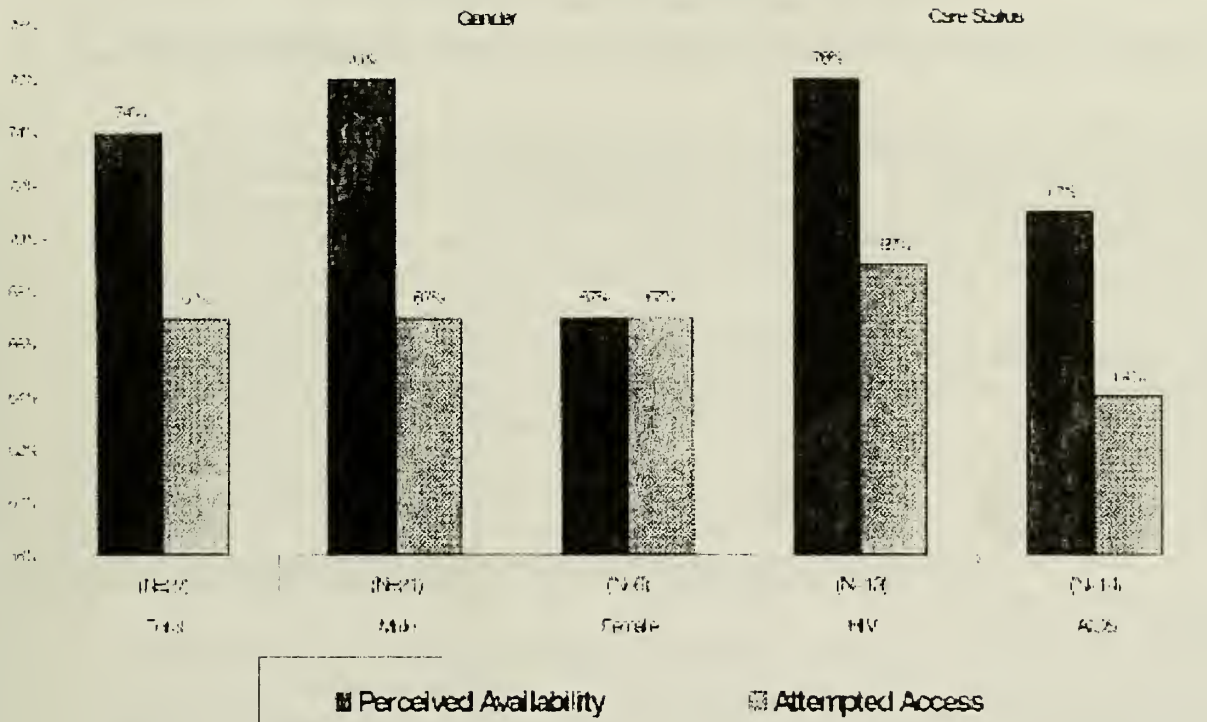
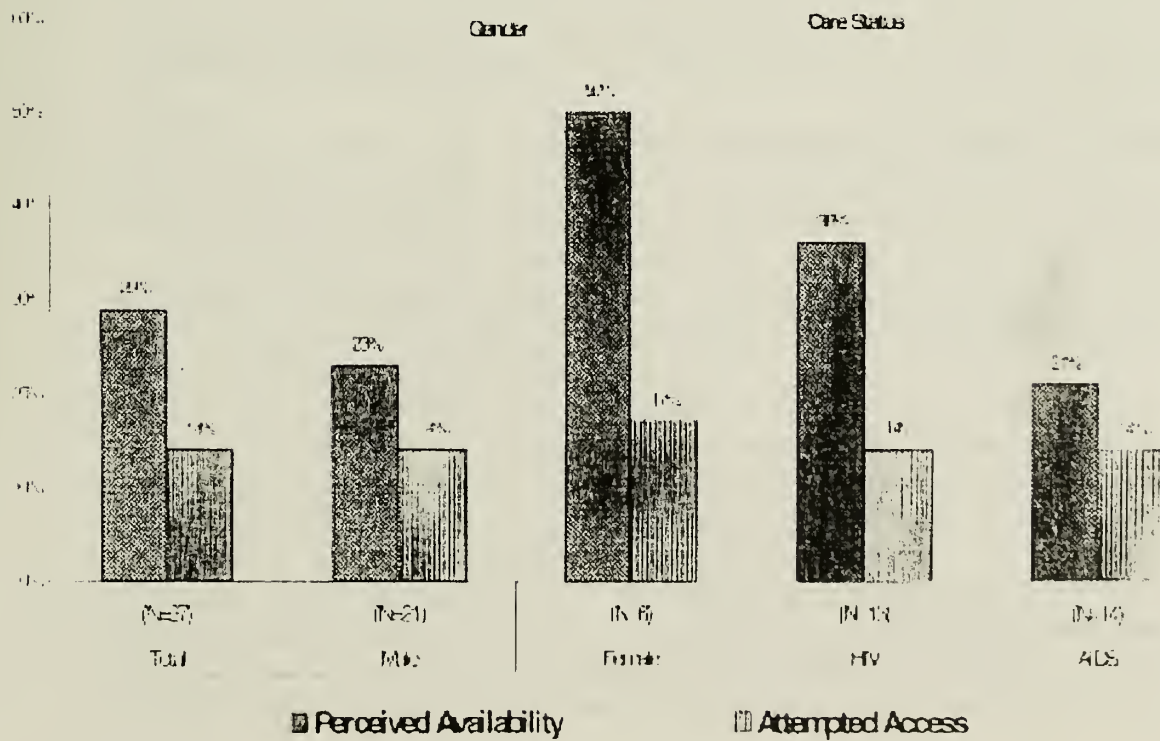


Chart 10d: Legal Services



***Overview of Focus Group Analyses***  
***Summary of Major Need Issue Themes From Each Stakeholder Group***

<b><u>Focus Group #1 <i>Persons Living With HIV/AIDS On Guam</i></u></b>	<b><u>Focus Group #2 <i>Medical, Health and Social Services Providers</i></u></b>	<b><u>Focus Group #3 <i>Family and Caregivers of PLWHA</i></u></b>
Problems with Confidentiality (privacy)	Problems with Confidentiality	
Issues with medications and treatment: Medical knowledge of HIV/AIDS; Patient confidence of doctors and Patient-Doctor relations (e.g. explanations such as side effects of medication)	Issues with medication costs, distribution, availability, adherence to treatment plan)	Issues with medications  Insurance/MIP issues
Psycho-social issues (mental, spiritual, social, family, etc.)	Psycho-social issues	Psycho-social issues
Case Management/Service Eligibility issues (MIP, Food Stamps, GEHRA, etc.), and coordination or linking of programs (grouped case study, advocacy network)	Case Management issues	Case Management issues and HIV services issues
Information center and outreach education, 24 hour assistance (Public service combination website, hotline, tapes), for caregivers, families and care prevention, etc information		Educational Issues and Barriers

## Focus Group #1 Persons Living With HIV/AIDS on Guam

### Problems with Confidentially (privacy)

- I am uncomfortable about going there. I think they are video taping and I feel uncomfortable. Only close friends know my situation. My family reacted with rejection, when they found out, they don't want to have anything to do with me.
- And privacy! My family found out I have HIV from the hospital and my family kick me out. They (GMH) discussed my medical situation to them (the family) that is why I became homeless. I don't know how I got the disease through sex or needle, blood.
- I'm concerned about confidentiality and that video camera at Public Health, we need to look over this issue because it scares people, what we sign for confidentiality and there is a video camera right there. We got to really work on Guam Confidentially.
- There's no privacy when applying.
- A lot of government workers are not trained with confidentiality.

### Case Management Issues: Eligibility for service-GHURA, MIP, Food Stamps)

- My situation is kind of different, because I am not a U.S. citizen. I qualified for MIP and I am eligible for services from GHURA.
- What I am living off of is from my previous job. Now I go to Salvation Army or the Catholic Social Service food bank or friends. I don't qualify for food stamp or welfare. (Coral Life and Public Health individual staff) also extend their hearts out to me and we need more people like them.
- I do know of one person who is not getting services. I encourage him to see (DPHSS staff). He was really getting sick and he lost his job because he was getting sick. I was helping him when I was working. He is really afraid and doesn't know where to go.
- At Public Health, when applying for food stamp, they ask question as to why you are applying for food stamp.
- (But) My living conditions is really bad – it's not fit for humans but I have to stick with it (because) that's what I have.
- The medicines that I'm getting are being paid by the Ryan White program, without that program I would be dead right now. We just lost our insurance and were under MIP then they kick us out of MIP and we were struggling to pay for this medication. We both don't work and we can't afford 3000.00 dollars in medicine a month. Then I talk to the service provider for my situation and mention a program and said that I was qualified.
- I don't feel comfortable going to Public Health – better medical care, we need funding for medication, and most of the pharmacy do not accept MIP – I'm still waiting for medication for about 4 weeks. There is a program at CDC (Public Health) office but we are put on the waiting list. I'm relocating to California because of problems with MIP, and the physicians here on Guam are not really qualified. I am afraid with all the problems going here on Guam.
- My thought – dream – is if mention that I have AIDS, does that put me higher on the list?
- The only services that we look for is with Dr. (name of private psychologist) who really help us and doesn't ask us for any fees. The other services look through is like GHURA and MIP, food stamps – these programs didn't matter if you had HIV or not, only matters on



- what your income is – if you are over the amount, then you cannot get in, which made it difficult for us. You have to be homeless or live in a car, in order for services to be provided. We went through bankruptcy, but because we were receiving social security we were not qualified. It is very hard to come from a middle class to make yourself poor. There is no break, either you are poor and get services or if you have money, you cannot have the services. It does limit us – it doesn't matter, if you are HIV, if you have income, then you don't qualify for services. Why do we have to quit a job to get services. The Ryan White is one good example to help somebody.
- *[PROBE What about the services that you are getting to deal with your conditions?]*  
Medical Social Services (MSS Public Health) with (staff name) who helped me out to find out a lot of services, and deal with MIP and just being around. (Name) gives me an uplift feeling that makes me want to keep ongoing. Services that are available, I had to go through (Coral Life Foundation staff) to find these services. I created an AIDS directory (with STD/AIDS program at Public Health). There are still services out there that I don't know about. (Coral Life Foundation and Public Health staff) helped with stress and depression. I am a member of MIP and even with that they haven't paid some of my bills – my bills have been referred to a collection agency. I don't qualify for food stamps or welfare. I was employed up to July. It is comforting to know that there is someone out there that is willing to help. We need more people like (the individuals at CLF and MSS/DPHSS).

#### **Psycho-social aspects ( mental, spiritual, social, family, etc...)**

- My family (too), they don't want me on island that's why I came here and also for the medical attention that I need.
- It would be nice to have services that can help parents speak to their children about it. We talk to our kids about our situation and they understand us.
- Can I really trust these people, hospital created the problem? I am alone and now I turn to the church.
- My daughter doesn't share our situation with other people.
- Our culture is supposed to be a very tight as family, but now a days, sometimes family hurt you more than help you. My wife's family is good and they support us a lot. The church here on Guam, they haven't really go out. I haven't seen a Catholic priest go out even when someone dies. They just don't do that – maybe it is not part of their job, I don't know. People need spiritual support. A lot of the Catholic family and churches only give when you come to them. Sometimes, you give them more than what you get. They make so much money every Sunday.
- I'm thankful for SDA- they're compassionate.
- I go to (my village) church and they help me a lot. I don't qualify for many service because of my citizenship.
- My son lives in the states, he said it's not a disgrace, it's only a disease. It took me two years to deal with what I have. But it will be totally another issue to deal with my family in Palau.
- When I need to talk to someone I bother (staff at Coral Life Foundation, and Medical Social Services, DPHSS). With (them) it really comforts me and they understands me.
- We've been lucky because of our sickness.
- MSS Public Health, Coral Life Foundation, and Salvation Army — they inform me of these services. My family really abandoned me, because of what I am.



- We've accepted what we have and some of our family haven't totally accepted it yet. We don't mind telling people what we have, but my families are saying that it will come back to us but our family don't want us to let anyone know. We want to volunteer for a lot of things, like talk to kids, and people, but our psychiatrist said not yet because the family is not ready. CDC (Public Health) has helped us and we feel comfortable there. (Local HMO) we feel comfortable there with them, the Doctors are very patient and we feel comfortable with them. When we first told my son and daughters what mom has, they weren't scared because they knew a lot about it.
- Medical Social Services (Public Health), and Coral Life are about the only ones that responded to my needs, they are my motivation. But also the Salvation Army, and Catholic Social services helped me once with food. I am afraid to encounter someone who has negative response. I don't need anything to bring me down. I do get a little assistance from CDC (Contagious Disease Control, DPHSS).
- We really need case management, a lot of us go through stress and depression.

**Information center and outreach education** 24 hour assistance – Public service combination (website, hotline, tapes), (programs grouped, one-stop support) for caregivers, families and care prevention, etc information.

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- Living here on Guam we don't have calling in services (hotline with information).
- The agencies should work together because there is really no communication- you get the run around. We need a one stop area (one location) for the people with this disease. There are a lot of services, but a lot of times we don't know what the services are.
- We need an information expert hot line or something – if you are a patient or have some symptoms that you are going through even emotional or mental because of your condition. Where you can pick up the phone and call someone who can help you out. I am diabetic and there is a lot of information services for that disease. I know we only have one (HIV/AIDS) doctor here. I've called Hawaii for information on HIV and they helped me and they asked if there are services out here. Well, if we can get a hotline that can provide these services to answer our questions and fears. If we can have a doctor that we can talk to over the phone about issues that can be resolved rather than to go in and see them.
- Resources for AIDS persons
- We educate them; some schools talked about HIV – but most of the time we educate our children, we tell them how you can get it. As far as counseling for our kids, and support for spouse here in Guam we don't really have that so we end up teaching our kids about it. Our children have learned – we told them what may happen to people with HIV, they know it is a disease, just like any disease, they are still looking for cure.
- Public transportation - how can we get transportation to and from clinics.
- Guam has not been educated enough to accept HIV/AIDS, In the mainland, you can walk into a clinic and say you have HIV and they will provide the services. Because we don't have these services, a one-stop place; but we don't need a sign that says for HIV only! If we can go to Coral Life and let them know we have AIDS, Coral Life can refer us to doctor, and provide documents to GHURA needed to provide for AIDS housing, or ask

- Public Health to provide caseworkers. If there is a facility that a person can go to that can get multiple services (Food stamp, MIP, Housing), the less contact we have with the community, we don't need that stress. Coral life does it and we can freely walk in there and ask questions and they know how to handle you, it is a free communication going back and forth.
- We don't have people helping keep an AIDS support group.
- Also, more communication, better communication with public agencies here in Guam. We need to have some kind of organization base for HIVAID. I'm tired of running around. Can it be all in one place? Lack of communication and the base of operation. We need just one place to get everything to solve problems.

**Issues with Medication/Treatments:** Medical knowledge of HIV/AIDS explanation - side effects of medication (explanations).

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- The hardest thing(s) living with HIV are medical care, getting medication, and with the insurance! MIP insurance is really going bad; it's hard for me to get medication. I still haven't gotten my medication and I just don't know what is going on in side (of me). And having doctors to look through books to find and figure out what is wrong with me. For instance, I was at (a local HMO), I had insurance with (company), and now I know I was dehydrated; I was really dehydrated but the doctor sent me into a room to get some rest while he read into a book! For three hours I laid there before he figured out that I was dehydrated and had to be rehydrated, and that scares me. Another thing is Public Health just (giving) you referrals and not having the service. (For example) I need catscans, I've had to have many catscans done and they still don't know what's wrong with me. That really worries me. I've been having a lot of problems like that. It's really hard
- I went to hospital and was admitted. That was my first time when I didn't know I had this disease – it me two years (to find out). I was surprised. For medical attention and services I qualify for MIP. That's why it's a good insurance, in my need for help they help me a lot; because right now I see Dr (name).
- The services here are good. Let's start with medical. When I went to see Dr. (name), they said that this is a medicine that you should take, but look (at me)! I broke out! They should let the patients know what the side effects are so that we know how to deal with it when it happens. They need to inform us so that we know what to look for.
- What will help a lot and when we have questions we can ask the doctors but with the pamphlet it is not very informative on the side effects.
- More doctors needed who know about AIDS disease.
- There is no cure for AIDS they are still practicing so they so should have that service for the island. *[PROBE What do you mean?]* They are still trying to learn and figure it out, and getting information along with you.
- I agree with the others on medication. When taking the medication, there are side affects. We wanted to know how long the side affect will last. The doctor said that all medication will give side affects. Lot of times we were just as good as the doctor – knowing which medication is causing this side affect and many times they don't know which exactly the medication that gives the side affects. I understand it is part of the drugs, but is it for the rest of life, or temporary? A lot of times the doctor cannot answer. *[PROBE Does anyone else have thoughts on this?]*

- They (doctors) should show both sides— what are your benefits and what is it if it doesn't work. So at least I know the two kinds of information, because I was doing good, but now look at my body. It scares me to take the medication and not knowing about it.
- What you are taking about is true, I was in the situation, I was given a medication, my feet will swell up, loose hair, it started when I took the medication. Even Dr. (name) doesn't know what it is. I went through six or seven medications, and everyone of them I have bad side effects. Throwing up, loss of appetite and loose a lot of weight, breaking out, irritated, sweat and feel a burning feeling on skin and I know it's from the medication because there's nothing else. I mean what else can it be. It is really scary. I am worried about the new medication that is coming in. I am concerned should I take this, what would my side effect would be, is it something that I'm going to hate later and would it hurt me more. I know it will help me in other ways, but at the same time its damaging.
- For me, it's the lack of information
- What disappointed me is the doctor gave me the choice of what medication to take. I don't know anything about this medication and what is it going to do for me. I shouldn't be given that opportunity to choose, because what if I choose the wrong one and it hurts me.
- Can I add something? The medicine, for example Bactrum, when I took that medication I almost died. They had me hospitalized for 5 or 6 days when they gave me that medication I asked what is that for and they answered the treatment. But they should be more informative on the medications given.
- The difficulty here is that they just hand the medication and with instruction and they don't explain verbally to the patients.



## Focus Group #2 Medical, Health and Social Services Providers

### Problems with Confidentiality

- Problem with confidentiality
- Confidentiality should not be a barrier to providing health
- Distorted image of confidentiality in different agencies – in the process of protecting ourselves we lose the patients – education is the key
- Hiding the disease is not going to help – education may start with providers – confidentiality becomes an issue when it hurts the patients
- HIPA law about confidentiality – need to maintain confidentiality yet share the services
- Due to problem with confidentiality many PLWHA do not go to get tested therefore they are not in service
- Using number codes on blood test request forms instead of writing “HIV/AIDS testing” on forms sent to the labs.

### Case management issues

- Lack of HIV/AIDS knowledge in the caregiver community
- a case manager needs to pull in all the other agencies a case manager needs to pull in all the other agencies
- Service providers need to know what services are available so a case manager knows all the outlets
- Have a designated case manager who contacts other agencies – not 5 different people from different agencies contacting the PLWHA
- Patients willing to test during screening but then we can't find them for follow up testing to confirm
- Need funding for capacity building – even Coral life doesn't get money for Case management
- Zero funding for case managers – all care is volunteer based – need to create a position
- Concept of treatment has to change – need “wed” or link together all services so that we provide holistic care.
- Once testing is done- too many patients don't come back, we (at primary care service) – loose contact and can't follow up with them.
- More non-profit community organizations that address particular need services for PLWHA
- All health care providers need to be involved – large groups sometimes loose track of patients – smaller group of care giver provides patients with whole care
- We need coordination for sure and perhaps primary care physician should be the conductor like any other disease Like cancer, we know the diagnosis of cancer but then you sit with your patient and explain that I am going to be your primary care doctor but I would have to send you to a surgeon for this if we need to get tissue from you to send it to oncologist; for this we need to have treatment therapy; but I will always be your family doctor. If you see any of these service people and you are not satisfied then get back to me and either I will get to or I will instruct the specialist to please give me that information or give the information correctly to my patients However, too many people don't know who their regular doctor is and maybe with the AIDS issue you



- need to develop the system with case management and work hard to get each patient to have a primary doctor, because that's the one will be working with them. But I really feel that as we start seeing the brunt of this epidemic in the region coming to Guam, we are going need family doctors or primary care physicians, and internist who can take lead as the key point of information and care coordination.

## Psycho-social issues

- Break down the stigma in the families by media campaigns and more public forums will break down walls
- Public Health only has 2 clinics that really handle acute care but chronic patients are left behind – not enough time to meet with all patients – we need resources to be able to make appointments for whole families
- Acute care (biogenic) vs. chronic care (sociogenic) – are different but the mind and heart must be part of healing.
- Education for individuals and families who don't accept patients once they find out they have AIDS
- There is a need to increase programs facilitating support groups for PLWHA; at present there's only a men's group
- One example is patients told family he has cancer
- Sensitivity training to feel comfortable with patients and to develop a working relationship acknowledging the patients' humanity.
- Any patient, not just those with this disease, need 'doctoring.' I'm here not to give medications but to deliver medical care. (There are barriers due to differences between people –rich or educated patients versus poor and less educated) that affect access to medications, but they all need information to understand their disease condition, symptoms and treatments; they need someone to sit down with them. They have fears, such as "If other people know about this, will I loose my job?"; the stigma (is intense). We need to get people (the community in general) to see (HIV/AIDS) as just another disease. The medical care system (on Guam) doesn't yet have the mechanisms to handle HIV/AIDS like it does TB, or diabetes, or cancer. People with these diseases have support and community groups educating the public to be aware, working against people's fears and fundraising to sustain community action."
- We must look at the patient's need according to the stage of their disease. There are different stages with this disease. I think people should understand that at the early stages – only with HIV - many of these people don't have many needs. When you think about it they are healthy people living with a deadly disease, for the most part they don't feel bad and they are able to engage in sports and anything that is pleasurable for them. They are not sick people but they certainly have a fatal disease. For us to give them what they need we must understand the stage of their medical condition. I can't force anyone to go see a counselor if they don't want to. What you can do is offer them the services that are available. But it is very important that primary care medical professionals have the information to tell patients that Guam has people to assist you – or doesn't have them. I want to know that I am your doctor and you have this diagnosis, and you and I will work through your needs. I think our primary care and social care services must develop the capacity to handle HIV/AIDS in the same manner we do for other diseases. I really have two points; one is that for the most part these people are healthy, they act

- healthy they live healthy, feel healthy and so realistically their needs are going to be determined by that. Second, they are to determine what their needs with their primary care doctor and health care staff must be able to give them information about services at the time that they need it; that is the time that we can offer it to them to say, okay you access it, but when the time comes that you are going to need this type of assistance let me know so I can help you.

### **Case Management Issues: Access and Eligibility to services**

- Guam Legal Services can't solicit clients they clients have to come to them, or other caregivers need to let PLWHA know about legal services available - Legal service advocacy is limited
- Transportation to get to doctors, pharmacies – problem with public transportation
- Housing
- Thru physicians, pastors, and word of mouth
- Guam only has 2 insurance providers that cover screening tests; all other insurance companies refuse to pay for screening since it's provided "free" by DPHSS.
- Primary care doctors are the one seeing these patients and we may not be fully aware what services are available to us. I believe that the primary doctors should be the transmitter of information.
- Funding problems from local/federal for MIP
- DPHSS – Directory of Services on Guam for PLWHA (passed out to participants)
- Limited services offered in Guam
- Housing is important
- Even care givers are unaware of HIV/AIDS services available on Guam
- Services are limited on island – advocate more community based organizations since they have more freedom than government agencies
- Train shelter staff to test Guam Homeless population for HIV/AIDS – staff is willing to work with DPHSS
- Nutrition therapy and recommendations are limited due to the fact that the nutritionists' at GMH and working at clinics are not in contact with patients until the condition of HIV/AIDS patient gets bad – in the late stages; – due to the terminal care status of patients we can't be effective. Nutrition services need to be in contact with patients in the early stages not at the end
- Wills and other needs of PLWHA are hard for Guam Legal Services because of our program grant funding and limited resources- unless they are senior citizens, or low income
- The big sign MENTAL HEALTH deters people from seeking services at the Department of Mental Health & Substance Abuse. This blocks their access to us.

### **Issues with medication (cost and distribution treatment)**

- The medical health care system has to develop ways to get the medications to people in a cost-effective way for all players in the supply/demand process, from suppliers and distributors to doctors and patients.
- Anyone at risk of sexually transmitted disease raises the risk of AIDS. It raises the physicians attention but if you came to me and said "I got a drip or this and that kind of thing," then I will say, let's test you for STD's, but I need to talk to you about the potentials of HIV; but I don't think that we should ever request an HIV test with out the patient knowing.

- I've had 4 patients. You ask, how do you feel now, as you advise them on medications, and then add, "well, I'm going to give you a medication that has side effects that will make you feel worse — it's a built in human problem for all diseases, but for a terminal disease like this or some cancers, the treatment won't cure you but can prolong your life for a time. If you're feeling good and not suffering a symptom people find it more difficult."
- GMH doesn't have an out patient assistance
- Patients are dealing with other problems (housing, food, etc.) HIV medications fall behind
- There are islanders from Northern Marianas who come to island to fill prescription
- Lack of basic medications – due to lack of funding
- There are people with access to free or inexpensive travel so there are patients going to HI and CA to access health care.

### **Focus Group #3 Family and Caregivers of PLWHA**

#### **Issues with Medications: Medical barriers**

- My (person) was on MIP.
- Getting medications. It's difficult finding people who can explain things about the new cocktail combinations; even the doctors don't know; we're getting help from our off-island doctor and on the Internet. But the medications are expensive and the insurance company has payment limits. They have the right to 'pull the plug' when you go past your limit –It creates fear in you. Also, they say that 'hospice' is paid for but Guam doesn't have a (hospice) facility, there's a difference and it's not 'home care'. I just have to go along with whatever they say."
- The hardest thing was trying to understand what (person's) needs were, especially when it came down to medication. (S/he) knew what (s/he) wanted but they didn't have it here in Guam. (person) had to tell the Dr. what to do.
- has a doctor (off-island) who has lots of patients and is a specialist in HIV and AIDS." "... the discomfort and stress and pain are troubling and there are needs for massage therapy or acupuncture treatments to help in addition to medications. This disease is progressive, it doesn't get better, and all you can do is arrest it – slow it down.
- Under Medicad, and were under MIP. The cost of medication has gone up to \$2000.00 but we still pay for 20% of our medication. My (person) does not need to pay for medication (which) is under the Ryan White grant.
- My (person) is under MIP and disabilities, MIP there are limits to payment so we (family) have to cover the rest.
- Really, it's the lack of medical and doctor expertise on our island. They need help to be able to learn about the medications, what might be going wrong, and what we should do
- Doctor expertise needs to be developed and treatment services are weak
- It is important that I know that the doctor has treated other persons of the same kind of disease.
- Medicaid isn't being accepted by the 3 pharmacies on-island. The problem is with the government not paying and insurance companies



## Insurance issues

- Insurance companies, especially when getting medication
- We have changed insurance companies. We used to work with (off-island pharmacy) to get (his/her) medications. They were good, and for a while (we) had (Guam insurance) as our insurance when they covered GovGuam, but they stopped, so now we're under (Guam insurance), they've not been as helpful. So, we have prescription pharmacy services and the insurance. We have an on-island family doctor, but none of Guam's doctors have the specialty expertise that a person with AIDS needs and wants.
- -insurance company run-around and restrictions. -
- Insurance coverage and restrictions

## Psycho-social issues

- No, but as I say we've been lucky. We've been very lucky and have not had any difficulty, so to speak. Our family has lots of community contacts and personal relationships with relatives and people all through the community.
- Couples For Christ has really helped us; people who have faith
- Interaction is mostly with family and friends
- Active in church, and (our clinic) Doctors help and pray with (him/her).
- Through there faith everyone is a child of god.
- Support group are very important
- My (person) was working at the time which helped (him/her)
- You get surprised by new problems that come along, and I'd been noticing (mental health symptoms). Dr. (name) who says this is a physical brain thing from the disease affecting memory and emotional moods, not just depression.
- (At my HMO/clinic) They don't treat the disease but the person which makes the person feel good.
- I am a working mother, with 3 kids one who has hemophilia and a (person) who has been living with AIDS for 15 years. My (person) has mood swings, a person who just sleeps a lot and lives with a lot of pain and takes lot of pain medication
- I've been able to do this because of spiritual need and sharing. I've called upon a higher power – as they say in the programs, but the way I've found to solve the problems we're struggling with is one-on-one, and I'm building a relationship between me and that worker, building trust, and I don't have the words other than to say that that relationship includes "the Spirit", "God," what ever term
- My friend, who started out sick, took the test but it was sent off island and got lost, and month later it came. When they knew (s/he) had the disease nurses at GMH were afraid; the treatment he received was not good. I feel that people are not educated and that more needs to be done in helping professionals work with these patients.
- (Many PLWHA)- I see, don't have a spouse or person like me; if it were just up to (my person), if (s/he) didn't have me to call or drive (s/he) would let it go—(s/he is) often weakened at times, and the mental changes caused by this disease are growing. " .... "I was ready for doing this, but some people aren't; I don't know, it was my past experiences, a time in my own life. The point is others may need help so they can help (to be caregivers)." ...



- Where I've come to know other (PLWHAs) persons, they've been trying to act normal, caring for themselves as long as they're feeling ok, but then when the later stages come on they don't have any family who's been working with them.
- Finding a person (at the service) who responds to me and my questions. I'm taking care of (a person) but I need someone to help me, to work with me when I need to go from office to office, desk to desk. I'm calling out, just tell me what can I do that works! – that solves my problem. This is a fatal (terminal) disease, and I'm here looking for someone who will help. (for example), I found an angel in (our pharmacy), I say an angel came into my life, one woman who will call me even from her home; I have her name in my address book and it's the type of person who you thank God for.

### **Case Management Issues: HIV services**

- Customer service rep. should be trained, they feel like a number.
- Customer services is not good
- Train their employees
- There are individual that are very helpful and are willing to help.
- There are people in the services that are very helpful like (name) also for the service.
- Find some customer service rep. who are bitchy people
- More support and people willing to understand the disease.
- hemophilia organization
- I've found on-line help, "Project Inform" from San Francisco, CA. Also I'm working with DPHSS
- Guam is in need for legal services for PLWHA.
- I have look into it but the only one that I know of is the Guam Legal Service which are focused to servicing persons with disabilities. They are limited with their services. I don't think that there is a legal service on Guam that provides for PLWHA
- I think that if more PLWHA persons come out then they will give us more grant money.
- (I care for a person) who is HIV and 3 kids. The problem I face is with services, there's no link between services, and doctors are not to educated about HIV and AIDS. Every time we apply for services we have to explain why we're applying.
- With Guam Legal Services they provide more for persons with disabilities and other legal services are limited.
- The services that we had in Hawaii were better because they offered more to help with HIV/ AIDS. Also the staff were very helpful.

### **Educational Issues and barriers**

- For the professionals and community to be more educated on HIV/AIDS so PLWHA would be comfortable of the disease (AWARENESS ON DISEASE)
- Educate our children on HIV/AIDS.
- To be more educated and learn more about HIV and AIDS. If people know about it, then the stigma would not happen. If more people were educated about it people would respond to it better.
- For me it was a leaning experience. I want people to be more educated about it and that people who live with AIDS should be open up.
- People need to be more educated and more understanding with the disease.

## Supporting Evidence and Detail Information on Service Needs Identified In The Needs Assessment Study

### Medical Treatment Needs (General)

#### Survey of PLWHA Findings (source: Table 4a)

#### Summary Grouping of Service Needs-Mean “Importance”

Rank #	Category	<u>Detailed Services:</u>	<u>Mean Scores</u>		
			<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
		Lab Work *	2.93	2.85	3.00
Highest (#1)		Appointment * (sig.)	2.86	2.71	3.00
Medical Treatment		Early Stage Care *	2.86	3.00	2.71
Needs (General)		Intermediate Stage Care	2.78	2.71	2.85
		Dental Care	2.59	2.38	2.79
		Late Stage Care	<u>2.59</u>	<u>2.50</u>	<u>2.69</u>
		<b>Medical Average:</b>	<b>2.8</b>	<b>2.7</b>	<b>2.8</b>

#### Focus Group Findings

##### Focus Group #2 Medical, Health and Social Services Providers

- We need coordination for sure and perhaps primary care physician should be the conductor, (For example) if you see any of these other service people and you are not satisfied then get back to me and either I will get to or I will instruct the specialist to please give me that information or give the information correctly to my patients. However, too many people don't know who their regular doctor is and maybe with the AIDS issue you need to develop the system with case management and work hard to get each patient to have a primary doctor, because that's the one will be working with them. But I really feel that as we start seeing the brunt of this epidemic in the region coming to Guam, we are going need family doctors or primary care physicians, and internist who can take lead as the key point of information and care coordination.
- Nutrition therapy and recommendations are limited due to the fact that the nutritionists' at GMH and working at clinics are not in contact with patients until the condition of HIV/AIDS patient gets bad – in the late stages; – due to the terminal care status of patients we can't be effective. Nutrition services need to be in contact with patients in the early stages not at the end
- The medical health care system has to develop ways to get the medications to people in a cost-effective way for all players in the supply/demand process, from suppliers and distributors to doctors and patients.
- Anyone at risk of sexually transmitted disease raises the risk of AIDS. It raises the physicians attention but if you came to me and said "I got a drip or this and that kind of thing," then I will say, let's test you for STD's, but I need to talk to you about the potentials of HIV; but I don't think that we should ever request an HIV test with out the patient knowing.
- I've had 4 patients. You ask, how do you feel now, as you advise them on medications, and then add, "well, I'm going to give you a medication that has side effects that will make you feel worse — it's a built in human problem for all diseases, but for a terminal disease like this or some cancers, the treatment won't cure you but can prolong your life for a time. If you're feeling good and not suffering a symptom people find it more difficult."

### Focus Group #3 Family and Caregivers of PLWHA

#### Issues with Medications: Medical barriers

- Getting medications. It's difficult finding people who can explain things about the new cocktail combinations; even the doctors don't know; we're getting help from our off-island doctor and on the Internet.
- The hardest thing was trying to understand what (person's) needs were, especially when it came down to medication. (S/he) knew what (s/he) wanted but they didn't have it here in Guam. (person) had to tell the Dr. what to do.
- has a doctor (off-island) who has lots of patients and is a specialist in HIV and AIDS." "the discomfort and stress and pain are troubling and there are needs for massage therapy or acupuncture treatments to help in addition to medications. This disease is progressive, it doesn't get better, and all you can do is arrest it – slow it down.
- Really, it's the lack of medical and doctor expertise on our island. They need help to be able to learn about the medications, what might be going wrong, and what we should do
- Doctor expertise needs to be developed and treatment services are weak
- It is important that I know that the doctor has treated other persons of the same kind of disease.

#### Medical Information, Consultation and Training on Patient Care

#### Survey of PLWHA Findings

(This Specific Need was Identified In Focus Group Data Collection)

#### Focus Group Findings

##### Focus Group #1 Persons Living With HIV/AIDS on Guam

~ **Issues with Medication/Treatments:** Medical knowledge of HIV/AIDS explanation - side effects of medication (explanations).

- I still haven't gotten my medication and I just don't know what is going on in side (of me) And having doctors to look through books to find and figure out what is wrong with me. For instance, I was at (a local HMO), I had insurance with (company), and now I know I was dehydrated; I was really dehydrated but the doctor sent me into a room to get some rest while he read into a book! For three hours I laid there before he figured out that I was dehydrated and had to be rehydrated, and that scares me. Another thing is Public Health just (giving) you referrals and not having the service. (For example) I need catscans, I've had to have many catscans done and they still don't know what's wrong with me. That really worries me. I've been having a lot of problems like that. It's really hard
- I went to hospital and was admitted. That was my first time when I didn't know I had this disease – it took me two years (to find out).
- The services here are good. Let's start with medical. When I went to see Dr. (name), they said that this is a medicine that you should take; but look (at me)! I broke out! They should let the patients know what the side effects are so that we know how to deal with it when it happens. They need to inform us so that we know what to look for.
- What will help a lot and when we have questions we can ask the doctors but with the pamphlet it is not very informative on the side effects.
- More doctors needed who know about AIDS disease.



- There is no cure for AIDS but they are still practicing [*PROBE What do you mean?*] They are still trying to learn and figure it out, and getting information along with you.
- I agree with the others on medication. When taking the medication, there are side affects. We wanted to know how long the side affect will last. The doctor said that all medication will give side affects. Lot of times we were just as good as the doctor – knowing which medication is causing this side affect and many times they don't know which exactly the medication that gives the side affects. I understand it is part of the drugs, but is it for the rest of life, or temporary? A lot of times the doctor cannot answer. [*PROBE Does anyone else have thoughts on this?*]
- They (doctors) should show both sides— what are your benefits and what is it if it doesn't work. So at least I know the two kinds of information; because I was doing good, but now look at my body. It scares me to take the medication and not knowing about it.
- What you are taking about is true, I was in the situation, I was given a medication, my feet will swell up, loose hair, it started when I took the medication. Even Dr. (name) doesn't know what it is. I went through six or seven medications, and everyone of them I have bad side effects. Throwing up, loss of appetite and loose a lot of weight, breaking out, irritated, sweat and feel a burning feeling on skin and I know it's from the medication because there's nothing else. I mean what else can it be. It is really scary. I am worried about the new medication that is coming in. I am concerned should I take this, what would my side effect would be, is it something that I'm going to hate later and would it hurt me more. I know it will help me in other ways, but at the same time its damaging.
- For me, it's the lack of information
- What disappointed me is the doctor gave me the choice of what medication to take. I don't know anything about this medication and what is it going to do for me. I shouldn't be given that opportunity to choose, because what if I choose the wrong one and it hurts me.
- Can I add something? The medicine, for example Bactrum, when I took that medication I almost died. They had me hospitalized for 5 or 6 days when they gave me that medication I asked what is that for and they answered the treatment. But they should be more informative on the medications given
- The difficulty here is that they just hand the medication and with instruction and they don't explain verbally to the patients.
- I'm relocating to California because of problems with MIP, and the physicians here on Guam are not really qualified. I am afraid with all the problems going here on Guam.

#### Medical Treatment Issues: Confidentiality

#### Survey of PLWHA Findings

(This Specific Need Only Identified In Focus Group Data Collection)

#### Focus Group Findings

##### Focus Group #1 Persons Living With HIV/AIDS on Guam

##### **Problems with Confidentially (privacy)**

- I am uncomfortable about going there. I think they are video taping and I feel uncomfortable. Only close friends know my situation. My family reacted with rejection, when they found out, they don't want to have anything to do with me.



- And privacy! My family found out I have HIV from the hospital and my family kick me out. They (GMH) discussed my medical situation to them (the family) that is why I became homeless. I don't know how I got the disease through sex or needle, blood.
- I'm concerned about confidentiality and that video camera at Public Health, we need to look over this issue because it scares people, what we sign for confidentiality and there is a video camera right there. We got to really work on Guam Confidentially.
- There's no privacy when applying.
- A lot of government workers are not trained with confidentiality.

#### Focus Group #2 Medical, Health and Social Services Providers

##### Problems with Confidentiality

- Problem with confidentiality
- Confidentiality should not be a barrier to providing health
- Distorted image of confidentiality in different agencies – in the process of protecting ourselves we lose the patients – education is the key
- Hiding the disease is not going to help – education may start with providers – confidentiality becomes an issue when it hurts the patients
- HIPA law about confidentiality – need to maintain confidentiality yet share the services
- Due to problem with confidentiality many PLWHA do not go to get tested therefore they are not in service
- Using number codes on blood test request forms instead of writing "HIV/AIDS testing" on forms sent to the labs.

#### **Financing Medical Costs (Case Management Services)**

#### Survey of PLWHA Findings (source: Table 4a)

##### **Summary Grouping of Service Needs-Mean "Importance"**

Rank #. Category	<u>Detailed Services:</u>	<u>Mean Scores</u>		
		<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
Tied 2 <sup>nd</sup> / 3 <sup>rd</sup>	Medical Costs *	2.82	2.64	3.00
<b>Financing</b>	Treatment Costs*	2.82	2.64	3.00
<b>Medical</b>	Financial Support *(sig.)	<u>2.62</u>	<u>2.23</u>	<u>3.00</u>
<b>Costs</b>	<b>Financing Costs Average:</b>	<b>2.7</b>	<b>3.0</b>	<b>3.0</b>

#### Focus Group Findings

##### Focus Group #1 Persons Living With HIV/AIDS on Guam

- The hardest thing(s) living with HIV are medical care, getting medication, and with the insurance! MIP insurance is really going bad; it's hard for me to get medication. I still haven't gotten my medication and I just don't know what is going on inside (of me).
- The medicines that I'm getting are being paid by the Ryan White program, without that program I would be dead right now. We just lost our insurance and were under MIP then they kick us out of MIP and we were struggling to pay for this medication. We both don't work and we can't afford 3000.00 dollars in medicine a month. Then I talk to the service provider for my situation and mention a program and said that I was qualified.

- The other services look through is like GHURA and MIP, food stamps – these programs didn't matter if you had HIV or not, only matters on what your income is – if you are over the amount, then you cannot get in, which made it difficult for us. You have to be homeless or live in a car, in order for services to be provided. We went through bankruptcy, but because we were receiving social security we were not qualified. It is very hard to come from a middle class to make yourself poor. There is no break, either you are poor and get services or if you have money, you cannot have the services. It does limit us – it doesn't matter, if you are HIV, if you have income, then you don't qualify for services. Why do we have to quit a job to get services. The Ryan White is one good example to help somebody.
- I am a member of MIP and even with that they haven't paid some of my bills – my bills have been referred to a collection agency. I don't qualify for food stamps or welfare. I was employed up to July. It is comforting to know that there is someone out there that is willing to help. We need more people like (the individuals at CLF and MSS/DPHSS).

### **Focus Group #3 Family and Caregivers of PLWHA**

#### **Financing Medical Costs**

- the medications are expensive and the insurance company has payment limits. They have the right to 'pull the plug' when you go past your limit –It creates fear in you. Also, they say that 'hospice' is paid for but Guam doesn't have a (hospice) facility, there's a difference and it's not 'home care'. I just have to go along with whatever they say."
- Insurance companies, especially when getting medication
- We have changed insurance companies. We used to work with (off-island pharmacy) to get (his/her) medications. They were good, and for a while (we) had (Guam insurance) as our insurance when they covered GovGuam, but they stopped, so now we're under (Guam insurance); they've not been as helpful. So, we have prescription pharmacy services and the insurance. We have an on-island family doctor, but none of Guam's doctors have the specialty expertise that a person with AIDS needs and wants.
- -insurance company run-around and restrictions. -
- Insurance coverage and restrictions
- Under Medicaid, and were under MIP. The cost of medication has gone up to \$2000.00 but we still pay for 20% of our medication. My (person) does not need to pay for medication (which) is under the Ryan White grant.
- My (person) is under MIP and disabilities, MIP there are limits to payment so we (family) have to cover the rest.
- Medicaid isn't being accepted by the 3 pharmacies on-island. The problem is with the government not paying and insurance companies.

## Case Management Needs (Service Coordination, Information and Referrals)

### Survey of PLWHA Findings (source: Table 4a)

#### Summary Grouping of Service Needs-Mean "Importance"

Rank #. Category	<u>Detailed Services:</u>	<u>Mean Scores</u>		
		<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
Tied 2 <sup>nd</sup> / 3 <sup>rd</sup>				
<b>Case Management</b>	Service Coordination	2.71	2.50	2.93
Needs (Service coordination, information & referrals)	Treatment Advocacy *(sig.)	2.68	2.43	2.93
	Information & Referral *(sig.)	2.64	2.29	3.00
	Legal Services *	<u>2.61</u>	<u>2.36</u>	<u>2.86</u>
	<b>Case Mgt. 1 Average:</b>	<b>2.7</b>	<b>2.4</b>	<b>3.0</b>

### Focus Group Findings

#### Focus Group #1 Persons Living With HIV/AIDS on Guam

##### **Case Management Issues:** Eligibility for service-GHURA, MIP, Food Stamps)

- I do know of one person who is not getting services. I encourage him to see (DPHSS staff). He was really getting sick and he lost his job because he was getting sick. I was helping him when I was working. He is really afraid and doesn't know where to go.
- At Public Health, when applying for food stamp, they ask question as to why you are applying for food stamp.
- Medical Social Services (MSS Public Health) with (staff name) who helped me out to find out a lot of services, and deal with MIP and just being around. (Name) gives me an uplift feeling that makes me want to keep ongoing. Services that are available, I had to go through (Coral Life Foundation staff) to find these services. I created an AIDS directory (with STD/AIDS program at Public Health). There are still services out there that I don't know about. (Coral Life Foundation and Public Health staff) helped with stress and depression.
- Guam has not been educated enough to accept HIV/AIDS, In the mainland, you can walk into a clinic and say you have HIV and they will provide the services. Because we don't have these services, a one-stop place; but we don't need a sign that says for HIV only! If we can go to Coral Life and let them know we have AIDS, Coral Life can refer us to doctor, and provide documents to GHURA needed to provide for AIDS housing, or ask Public Health to provide caseworkers. If there is a facility that a person can go to that can get multiple services (Food stamp, MIP, Housing), the less contact we have with the community, we don't need that stress. Coral life does it and we can freely walk in there and ask questions and they know how to handle you, it is a free communication going back and forth.
- Also, more communication, better communication with public agencies here in Guam. We need to have some kind of organization base for HIVAID. I'm tired of running around. Can it be all in one place? Lack of communication and the base of operation. We need just one place to get everything to solve problems.

#### Focus Group #2 Medical, Health and Social Services Providers

##### Case management issues

- a case manager needs to pull in all the other agencies a case manager needs to pull in all the other agencies
- Service providers need to know what services are available so a case manager knows all the outlets



- Have a designated case manager who contacts other agencies – not 5 different people from different agencies contacting the PLWHA
- Patients willing to test during screening but then we can't find them for follow up testing to confirm
- Need funding for capacity building – even Coral life doesn't get money for Case management
- Zero funding for case managers –all care is volunteer based –need to create a position
- Concept of treatment has to change – need “wed” or link together all services so that we provide holistic care.
- Once testing is done- too many patients don't comeback, we (at primary care service) – loose contact and can't follow up with them.
- More non-profit community organizations that address particular need services for PLWHA
- All health care providers need to be involved – large groups sometimes loose track of patients – smaller group of care giver provides patients with whole care

### Focus Group #3 Family and Caregivers of PLWHA

#### Case Management Issues: HIV services

- Customer service reps. should be trained, they make you feel like a number
- Customer service is not good
- (Services need to)train their employees
- There are individuals that are very helpful and are willing to help, but you find many customer service reps. who are bitchy people
- There are people in the services that are very helpful like (name) also for the service.
- We need more support and people willing to understand the disease.
- (I care for a person) who is HIV and 3 kids. The problem I face is with services, there's no link between services, and doctors are not to educated about HIV and AIDS. Every time we apply for services we have to explain why we're applying.
- The services that we had in Hawaii were better because they offered more to help with HIV/ AIDS. Also the staff were very helpful.

#### Education Issues/Information to PLWHA, Family and Care Givers

#### Survey of PLWHA Findings (source: Table 4a)

##### Summary Grouping of Service Needs-Mean “Importance”

Rank #. Category	<u>Detailed Services:</u>	<u>Mean Scores</u>		
		<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
4th	Resource Guide	2.61	2.50	2.71
<b>Educational Issues</b>	Nutrition	2.57	2.57	2.57
<b>Information Needs</b>	Printed Information	2.57	2.36	2.79
of PLWHA and	Hotline	<u>2.21</u>	<u>2.14</u>	<u>2.29</u>
their caregivers	<b>Case Mgt. 2 Average:</b>	<b>2.5</b>	<b>2.4</b>	<b>2.6</b>



## **Focus Group Findings**

### **Focus Group #2 Medical, Health and Social Services Providers**

- Lack of HIV/AIDS knowledge in the caregiver community
- Any patient, not just those with this disease, need 'doctoring.' I'm here not to give medications but to deliver medical care." They all need information to understand their disease condition, symptoms and treatments; they need someone to sit down with them. They have fears, such as "If other people know about this, will I loose my job?"; the stigma (is intense). We need to get people (the community in general) to see (HIV/AIDS) as just another disease. The medical care system (on Guam) doesn't yet have the mechanisms to handle HIV/AIDS like it does TB, or diabetes, or cancer. People with these diseases have support and community groups educating the public to be aware, working against people's fears and fundraising to sustain community action."

### **Focus Group #1 Persons Living With HIV/AIDS on Guam**

**Information center and outreach education** 24 hour assistance – Public service combination (website, hotline, tapes), (programs grouped, one-stop support) for caregivers, families and care prevention, etc information.

- Living here on Guam we don't have calling in services (hotline with information.
- The agencies should work together because there is really no communication- you get the run around. There are a lot of services, but a lot of times we don't know what the services are.
- We need an information expert hot line or something – if you are a patient or have some symptoms that you are going through even emotional or mental because of your condition. Where you can pick up the phone and call someone who can help you out. I am diabetic and there is a lot of information services for that disease. I know we only have one (HIV/AIDS) doctor here. I've called Hawaii for information on HIV and they helped me and they asked if there are services out here. Well, if we can get a hotline that can provide these services to answer our questions and fears. If we can have a doctor that we can talk to over the phone about issues that can be resolved rather than to go in and see them.
- We educate them; some schools talked about HIV – but most of the time we educate our children, we tell them how you can get it. As far as counseling for our kids, and support for spouse here in Guam we don't really have that so we end up teaching our kids about it. Our children have learned – we told them what may happen to people with HIV, they know it is a disease, just like any disease, they are still looking for cure.

### **Focus Group #3 Family and Caregivers of PLWHA**

#### **Educational Issues and barriers**

- For the professionals and community to be more educated on HIV/AIDS so PLWHA would be comfortable of the disease. (AWARENESS ON DISEASE)
- Educate our children on HIV/AIDS.
- To be more educated and learn more about HIV and AIDS. If people know about it, then the stigma would not happen. If more people were educated about it people would respond to it better.
- For me it was a leaning experience. I want people to be more educated about it and that people who live with AIDS should be open up.
- People need to be more educated and more understanding with the disease.

## Case Management Needs (Daily Life and Housing Assistance)

### Survey of PLWHA Findings (source: Table 4b)

#### Summary Grouping of Service Needs-Mean "Importance"

Rank #. Category	<u>Detailed Services:</u>	<u>Mean Scores</u>		
		<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
5th <b>Case Management Needs (Daily Life and Housing Assistance)</b>	Transportation	2.57	2.43	2.71
	Housing	2.50	2.43	2.57
	Long-term housing	2.50	2.36	2.64
	Fiscal Mgt. (budgeting)	2.26	2.15	2.36
	Employment Assistance	2.36	2.50	2.21
	Rental Assistance	2.32	2.29	2.36
	Transitional Housing	2.07	2.36	1.79
	Child Care	<u>1.54</u>	<u>1.64</u>	<u>1.43</u>
	<b>Case Mgt. 3 Average:</b>	<b>2.3</b>	<b>2.3</b>	<b>2..3</b>

### Focus Group Findings

#### Focus Group #1 Persons Living With HIV/AIDS on Guam

- (But) My living conditions is really bad – it's not fit for humans but I have to stick with it (because) that's what I have. What I am living off of is from my pervious job. Now I go to Salvation Army or the Catholic Social Service food bank or friends. I don't qualify for food stamp or welfare. (Coral Life and Public Health individual staff) also extend their hearts out to me and we need more people like them.
- Public transportation - how can we get transportation to and from clinics.

#### Focus Group #2 Medical, Health and Social Services Providers

##### Case Management Issues: Access and Eligibility to services

- Guam Legal Services can't solicit clients they clients have to come to them, or other caregivers need to let PLWHA know about legal services available - Legal service advocacy is limited
- Transportation to get to doctors, pharmacies – problem with public transportation
- Housing
- Primary care doctors are the one seeing these patients and we may not be fully aware what services are available to us. I believe that the primary doctors should be the transmitter of information.
- Housing is important
- Services are limited on island – advocate more community based organizations since they have more freedom than government agencies
- Wills and other needs of PLWHA are hard for Guam Legal Services because of our program grant funding and limited resources- unless they are senior citizens, or low income
- Patients are dealing with other problems (housing, food, etc.) HIV medications fall behind

#### Focus Group #3 Family and Caregivers of PLWHA

##### Case Management Issues: HIV services

- I've found on-line help, "Project Inform" from San Francisco, CA. Also I'm working with DPHSS

- Guam is in need for legal services for PLWHA.
- I have look into it but the only one that I know of is the Guam Legal Service which are focused to servicing persons with disabilities. They are limited with their services. I don't think that there is a legal service on Guam that provides for PLWHA With Guam Legal Services they provide more for persons with disabilities and other legal services are limited.

### Psycho-social Need Issues (Mental Health)

#### Survey of PLWHA Findings (source: Table 4a)

##### Summary Grouping of Service Needs-Mean "Importance"

Rank #	Category	<u>Detailed Services:</u>	<u>Mean Scores</u>		
			<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
7th	Psycho-Social Issues (Mental Health)	Support Group Counseling	2.44	2.43	2.46
		Emotional /Practical	2.36	2.29	2.43
		Individual Counseling	2.22	2.07	2.38
		Family Counseling	1.93	1.79	2.08
		Couple Counseling	1.77	1.79	1.75
		Substance Abuse Counseling	<u>1.71</u>	<u>1.79</u>	<u>1.64</u>
		<b>Psycho-social Average:</b>	<b>2.1</b>	<b>2.0</b>	<b>2.1</b>

#### Focus Group Findings

##### Focus Group #1 Persons Living With HIV/AIDS on Guam

##### **Psycho-social aspects ( mental, spiritual, social, family, etc...)**

- My family (too), they don't want me on island that's why I came here and also for the medical attention that I need.
- It would be nice to have services that can help parents speak to their children about it. We talk to our kids about our situation and they understand us.
- Can I really trust these people, hospital created the problem? I am alone and now I turn to the church.
- My daughter doesn't share our situation with other people.
- Our culture is supposed to be a very tight as family, but now a days, sometimes family hurt you more than help you. My wife's family is good and they support us a lot. The church here on Guam, they haven't really go out. I haven't seen a Catholic priest go out even when someone dies. They just don't do that – maybe it is not part of their job, I don't know. People need spiritual support. A lot of the Catholic family and churches only give when you come to them. Sometimes, you give them more than what you get. They make so much money every Sunday.
- My family really abandoned me, because of what I am.
- We've accepted what we have and some of our family haven't totally accepted it yet. We don't mind telling people what we have, but my families are saying that it will come back to us but our family don't want us to let anyone know. We want to volunteer for a lot of things, like talk to kids, and people, but our psychiatrist said not yet because the family is not ready. CDC (Public Health) has helped us and we feel comfortable there. (Local HMO) we feel comfortable there with them, the Doctors are very patient and we feel comfortable with them. When we first told my son and daughters what mom has, they weren't scared because they knew a lot about it.
- We really need case management; a lot of us go through stress and depression.



## Focus Group #2 Medical, Health and Social Services Providers

### Psycho-social issues

- Break down the stigma in the families by media campaigns and more public forums will break down walls
- Acute care (biogenic) vs. chronic care (sociogenic) – are different but the mind and heart must be part of healing.
- Education for individuals and families who don't accept patients once they find out they have AIDS
- There is a need to increase programs facilitating support groups for PLWHA; at present there's only a men's group
- One example is patients told family he has cancer
- Sensitivity training to feel comfortable with patients and to develop a working relationship acknowledging the patients' humanity.

## Focus Group #3 Family and Caregivers of PLWHA

### Psycho-social issues

- You get surprised by new problems that come along, and I'd been noticing (mental health symptoms). Dr. (name) who says this is a physical brain thing from the disease affecting memory and emotional moods, not just depression.
- I am a working mother, with 3 kids one who has hemophilia and (my person) has been living with AIDS for 15 years. My (person) has mood swings, a person who just sleeps a lot and lives with a lot of pain and takes lot of pain medication
- I've been able to do this because of spiritual need and sharing. I've called upon a higher power – as they say in the programs, but the way I've found to solve the problems we're struggling with is one-on-one, and I'm building a relationship between me and that worker, building trust, and I don't have the words other than to say that that relationship includes “the Spirit”, “God,” what ever term
- My friend, who started out sick, took the test but it was sent off island and got lost, and month later it came. When they knew (s/he) had the disease nurses at GMH were afraid; the treatment he received was not good. I feel that people are not educated and that more needs to be done in helping professionals work with these patients.
- (Many PLWHA)- I see, don't have a spouse or person like me; if it were just up to (my person), if (s/he) didn't have me to call or drive (s/he) would let it go— (s/he is) often weakened at times, and the mental changes caused by this disease are growing. “ ... “I was ready for doing this, but some people aren't; I don't know, it was my past experiences, a time in my own life. The point is others may need help so they can help (to be caregivers).” ... Where I've come to know other (PLWHAs) persons, they've been trying to act normal, caring for themselves as long as they're feeling ok, but then when the later stages come on they don't have any family who's been working with them.
- Finding a person (at the service) who responds to me and my questions. I'm taking care of (a person) but I need someone to help me, to work with me when I need to go from office to office, desk to desk. I'm calling out, just tell me what can I do that works! – that solves my problem. This is a fatal (terminal) disease, and I'm here looking for someone who will help (for example), I found an angel in (our pharmacy), I say an angel came into my life, one woman who will call me even from her home; I have her name in my address book and it's the type of person who you thank God for.



### Medical needs: Late stage

#### Survey of PLWHA Findings (source: Table 4a)

##### **Summary Grouping of Service Needs-Mean "Importance"**

Rank #. Category	<u>Detailed Services:</u>	<u>Mean Scores</u>		
		<u>Total</u>	<u>HIV only</u>	<u>With AIDS</u>
6th	Late Stage-Hospice	2.41	2.38	2.43
Medical Needs	Late Stage- Burial	2.41	2.38	2.43
Late Stage	Alternative/Traditional	2.28	2.00	2.54
	Late Stage-Skilled Nursing	<u>2.26</u>	<u>2.15</u>	<u>2.36</u>
	Medical Average:	2.3	2.2	2.4

#### Focus Group Findings

##### Focus Group #2 Medical, Health and Social Services Providers

- We must look at the patient's need according to the stage of their disease. There are different stages with this disease. I think people should understand that at the early stages – only with HIV - many of these people don't have many needs. When you think about it they are healthy people living with a deadly disease, for the most part they don't feel bad and they are able to engage in sports and anything that is pleasurable for them. They are not sick people but they certainly have a fatal disease. For us to give them what they need we must understand the stage of their medical condition. I can't force anyone to go see a counselor if they don't want to. What you can do is offer them the services that are available. But it is very important that primary care medical professionals have the information to tell patients that Guam has people to assist you – or doesn't have them. I want to know that I am your doctor and you have this diagnosis, and you and I will work through your needs. I think our primary care and social care services must develop the capacity to handle HIV/AIDS in the same manner we do for other diseases. I really have two points; one is that for the most part these people are healthy, they act healthy they live healthy, feel healthy and so realistically their needs are going to be determined by that. Second, they are to determine what their needs with their primary care doctor and health care staff must be able to give them information about services at the time that they need it; that is the time that we can offer it to them to say, okay you access it, but when the time comes that you are going to need this type of assistance let me know so I can help you.

# Guam HIV/AIDS Care Plan

## **Guam HIV/AIDS Care Plan: General Recommendations**

The order of these issue concerns and recommendations does not indicate priority of any need item, objective, or goal. Following a standard format for planning recommendations in this report, we have organized information for each issue under headings of Existing Resources, Challenges/Barriers, and Recommendations.

### The Issue Concerns

- A. Continued community advisory involvement and input.
- B. Evidence-based information for decision-making and planning.

#### **A. Continued community advisory involvement and input**

### Existing Resources

HIV prevention planning on Guam has been carried out by the Guam HIV Prevention Community Planning Group (CPG) since 1994, under the auspices of the Bureau of Communicable Disease Control, Department of Public Health and Social Services.

HIV/AIDS care planning was initiated in 2001 under the needs assessment and planning project documented in this report, and it has identified the networks of people and organizational resources with the on-island experience and motivated interests to support continued community advisory involvement and input. Over the course of the project reported here, The Guam Ryan White Needs Assessment Advisory Council was organized and periodic meetings held from June 2002 through April 2003 (see Appendix A).

The Office of Minority Health (U.S. DHHS): Resource HIV Education and Training Center, in San Francisco, CA, offers technical assistance and training and is willing to assist Guam with training needs for advisory councils and community planning groups.

Federal program policy and requirements exist for continuing community advisory involvement and input to a continuum of care linking prevention and medical treatment care. HIV/AIDS care planning and prevention planning are conducted separately in many areas because the task functions are federally funded through separate division centers within the U.S. Department of Health and Human Services. The Guam CPG, which carries out prevention planning, is funded as part of the cooperative agreements funded by the Centers For Disease Control and Prevention (CDC). HIV/AIDS care planning in U.S. States and jurisdictions is through Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Title I and II planning groups, through cooperative agreements with the Health Resources & Services Administration (HRSA). Eligible Title II grantees for Ryan White Title II Consortia funding support (i.e., HIV/AIDS care planning) includes Guam as well as all other territories, the District of Columbia, and all 50 States, and Guam has been awarded Title II funding.

Continued community advisory involvement and input will not only be a requirement for future Title II funding, but for nearly all other grant sources – both federal and private foundations.



According to the application guidance for new proposals to the grant program for Outpatient Early Intervention Services (EIS) with Respect to HIV Disease, \* *Consumer Involvement* is a required policy and procedure for Title III EIS program operations:

EIS programs are required to demonstrate that consumers are actively involved in program development, implementation, and evaluation activities. "Consumers" are defined as persons living with HIV/AIDS (PLWH's) or their representatives (i.e., those who represent PLWH's who are unable to speak for themselves such as HIV+ children and severely ill individuals).

There are many ways to involve consumers, and each program should design consumer involvement that best suits its situation. To accomplish effective consumer involvement, programs should provide necessary training, mentoring, supervision, and reimbursement of expenses. Examples of consumer involvement are

- HIV consumer representation on the organization's Board of Directors.
- Establishment of an HIV specific Consumer Advisory Board
- HIV consumer representation on an existing consumer advisory board
- Involvement of HIV consumers on workgroups, committees and task forces, such as a Program Committee, an Outreach Task Force, or a Patient Education Committee.
- Using HIV consumers as volunteers, such as peer educators, outreach workers, or staff in a clinic.
- HIV consumer surveys, consumer forums, and focus groups
- Using HIV peer trainers to work directly with patients to help them address issues related to making healthy decisions, gaining access to clinical trials, managed care, etc.

HRSA expects collaboration and coordination between HIV/AIDS care planning and prevention planning. As stated in "Care/Prevention Collaborative Planning: HRSA AIDS Programs Title I and Title II Planning Bodies and CDC HIV Prevention Community Planning Groups," a guidance publication from the U.S. Department of Health & Human Resources (page 5):

The outcome of collaborative planning can be development of a more comprehensive continuum of care, with particular attention to the intersection between prevention and care. HRSA expects CARE act Title I planning councils and Title II consortia to coordinate local care planning activities with CDC's HIV Community Planning Groups (CPGs). Two particular areas of focus are outreach and reducing HIV perinatal transmissions, as follows:

- Coordination should occur in planning and delivery of local HIV outreach programs whose principal purpose is identifying people with HIV disease so that they learn about their HIV status and become enrolled in care and treatment services (Summary of HRSA Program Policy Notice No. 97-03. Outreach. Issued March 31, 1997).
- Coordinated planning should also occur in developing outreach activities ... to reduce HIV perinatal transmission rates. Especially important is HIV prevention planning for counseling testing and referral to care settings, as well as HIV services planning to meet ... treatment needs ... and therapy to reduce the likelihood of HIV transmission.

Regarding use of CARE Act Title I and II funds related to prevention activities, HRSA states that funds may be used for health education/risk reduction programs for persons living with HIV. These programs may provide information about medical and psycho-social support services and counseling or prepare/distribute materials in the context of medical and psycho-social support services to educate clients with HIV about methods to reduce the spread of HIV (HRSA Title I/II program guidance).

Ryan White Title III EIS Program, "Program and Application Guidance for New Competing Proposals: Outpatient Early Intervention Services (EIS) With Respect to HIV Disease," Health Resources and Services Administration, HIV/AIDS Bureau, US Department of Health & Human Services. April 16, 2001. pages 12-13.



Ryan White Title III EIS Program, "Program and Application Guidance for New Competing Proposals: Outpatient Early Intervention Services (EIS) With Respect to HIV Disease," Health Resources and Services Administration, HIV/AIDS Bureau, US Department of Health & Human Services. April 16, 2001: pages 12-13.

### **Challenges/Barriers**

- A "care" planning consortia or other mechanism for consumer involvement and community-wide service coordination must be organized. The only current entity is the Needs Assessment for PLWHA Advisory Council initiated under the needs assessment and planning project documented in this report, which will end with this project.
- The Guam HIV Prevention CPG has a written charter stating its mission and functions. The group's resources and the time that members of this group can devote to achieving its current functions are limited.
- Guam has been in economic recession for some time and the current budget "crisis" of the local government will severely limit local funding and staff resources to support community-wide, interagency planning bodies and activities.
- Federal HIV/AIDS funding sources have not increased for minority and marginal populations, and the current U.S. Administration and climate in the US Congress/Senate leaves the future of such funding uncertain.

### **Recommendations**

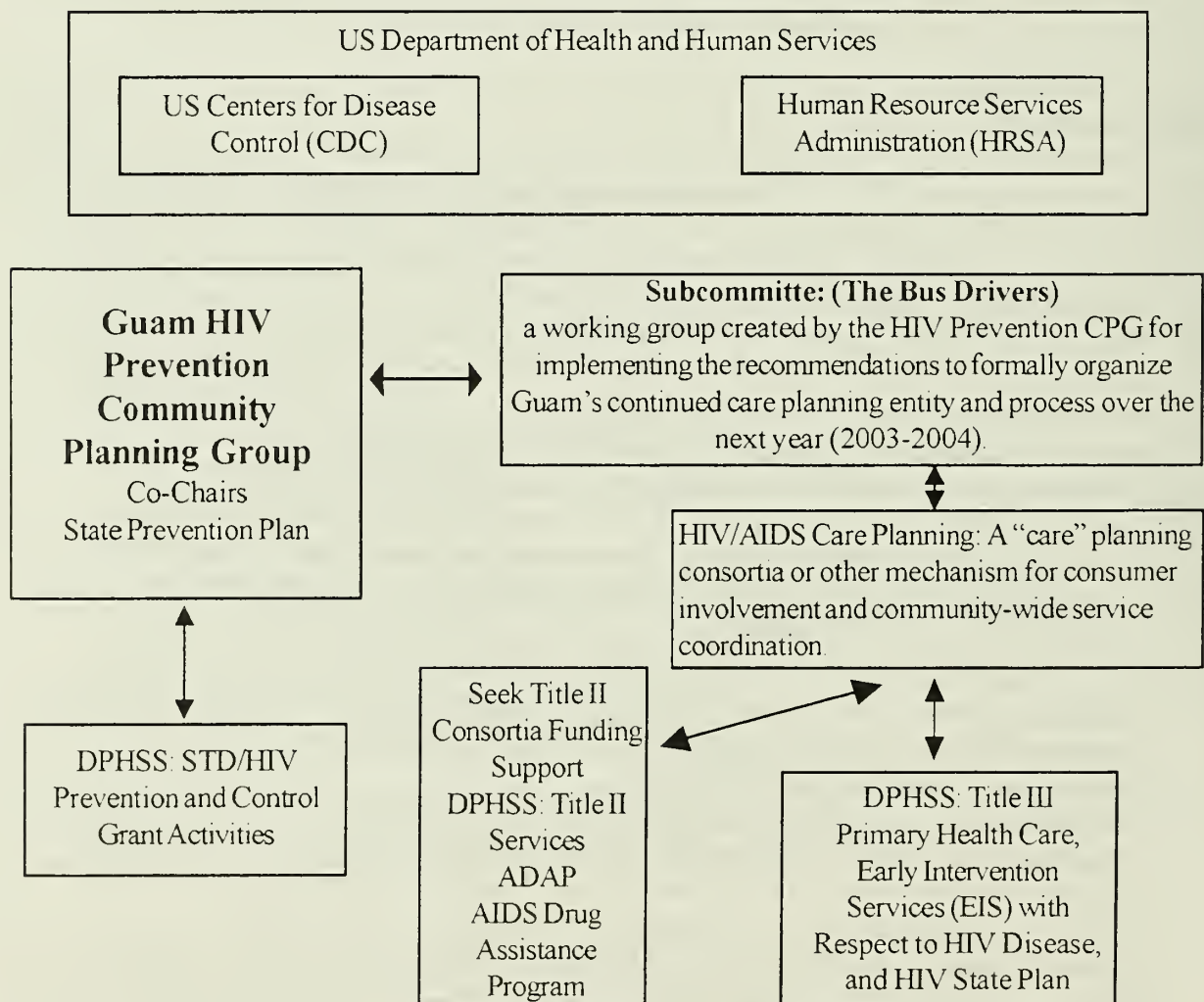
- Continued community HIV/AIDS care planning and consumer involvement must be formally organized and structured in a way that this function is sustainable and effective even in times of economic hardship limiting local funding sources, and without over dependency on federal funding which also cannot be guaranteed over the coming decade.
- The existing Guam HIV Prevention CPG Co-Chairs will form and task an HIV/AIDS planning subcommittee working group for implementing the recommendations in this report document to formally organize Guam's continued care planning entity and process over the next year 2003-2004 (see next page Vision for AIDS Care and HIV Prevention Merger).
- To fulfill the principle of inclusive participation which is shared by federal guidelines for both prevention and care planning, this Guam HIV Prevention CPG subcommittee should include persons from the several AIDS related non-government organizations which exist or are being organized, specifically Coral Life Foundation, Dream for a Cure, and GUAHAN Project, as well as any PLWHA who wish to participate.
- As a starting point, this Guam HIV Prevention CPG subcommittee should follow the guideline model as presented in a draft charter for an HIV/AIDS Care planning body prepared by a subcommittee of the Advisory Council for the Needs Assessment Study of Persons Living with HIV/AIDS on Guam (see appendix attachment).
- The Guam HIV Prevention CPG subcommittee group should also pursue possible re-establishment of a Governor's HIV/AIDS Interagency Task Force, which existed for a time in the early 1990s, as a possible strategy for mobilizing the limited resources and wide-network of AIDS related private and public services necessary to a continuum of care for PLWHA.
- The Guam HIV Prevention CPG subcommittee group should contact the Office of Minority Health (U.S. DHHS): Resource HIV Education and Training Center, in San Francisco, CA, to request training and technical assistance that will help achieve these recommended actions.

## Continued Care Planning: Strategy for development of an HIV/AIDS Care Advisory Council

This strategy for developing an HIV/AIDS Care Advisory Council was approved by Guam's HIV/AIDS Prevention Community Planning Group (CPG) on March 12, 2003. It was prepared by a subcommittee the Advisory Council For the Needs Assessment Study of PLWHA on Guam. The subcommittee members included Mr. Ed Taitano (2002-3 Guam CPG Co-Chair), Ms Rose Quitevas (Title II ADAP Coordinator, DPHSS), Mr. Terry Aguon (Medical Social Services, DPHSS), Ms. June Perez (Administrator of GMH Education and CME Program), and Ms. Brenda Delisle (Graduate Student in Public Health).

Statement: The HIV Prevention CPG will take an interim lead role to pursue the strategic plan recommendations developed by the needs assessment advisory group, and implement action that develops coordinated systems of prevention and care planning, ultimately resulting in reducing the number of new HIV infections in Guam and enhancing the quality of life for persons living with HIV/AIDS.

### Vision for AIDS Care and HIV Prevention Merger



## **B. Evidence-based information for on-island decision-making and planning.**

### **Existing Resources**

- Guam has several “health surveillance system” surveys and data sets, including the *Behavioral Risk Factor Surveys* collected and maintained by the Office of Planning & Evaluation at DPHSS, and the Youth Risk Behavior Surveys collected and maintained by the HIV/AIDS Prevention Program, Curriculum and Instruction, Department of Education. There are other Information record data sets, such as the Guam Blood Bank, that can be analyzed for insights to the epidemic on Guam.
- The Office of Planning & Evaluation, DPHSS can provide research and epidemiological assistance, and there are academic faculty at the University of Guam, University of Hawaii, and other universities who have experience studying Asian and Pacific Islander populations.
- Regionally, Guam has access to technical assistance and science based information from the *Secretariat of the Pacific Community* (formerly South Pacific Commission) and the U.N. World Health Organization.
- There are several national, non-government organizations that can provide technical assistance and or training to develop skills and capacity of on-island stakeholders so they can increase the production and application of science-based information in AIDS prevention and care planning. These include, but are not limited to:
  - The Behavioral & Social Science Volunteer Program (directed by the American Psychological Association Office on AIDS)
  - National Minority AIDS Council (NMAC)
  - Asian and Pacific Islander American Health Forum (APIAHF)
  - Asian and Pacific Islander Wellness Center (APIWC)
  - Pacific Island Jurisdictions AIDS Action Group (PIJAAG)
  - American Foundation for AIDS Research

### **Challenges/Barriers**

- Data analyses and reports written for member of Guam’s CPG, PLWHA, and community leaders are always in short supply and too often not available in a timely manner where decisions are to be made.

### **Recommendations**

- The Guam Prevention CPG should work with PIJAAG to expand the Guam “epi-profile” to include tabular comparisons of Guam measures to other regional island states, including the CMNI, FSM, the Republics of Belau, and the Marshall Islands, as well as the State of Hawaii
- The Bureau of Communicable Disease Control, will work with the Office of Planning and Evaluation, to get TA from HRSA and CDC to define program data requirements, and the data collection and reporting methodologies which can obtain useful and timely information for planning and programmatic purposes.



- The Guam Prevention CPG and proposed subcommittee for an AIDS Care Advisory group should begin implementing those sections of their charters addressing quality control responsibilities, or review and improve them.
- Obtain technical assistance to conduct at least one training for their members and stakeholders on how to develop an annual evaluation program that provides them measurement indicators of consumer satisfaction with the effectiveness of interventions and service programs

## **Guam HIV/AIDS Care Plan: Medical Care Issues**

### **Critical Needs, Existing Resources, Challenges/Barriers, and Recommendations**

The analysis and review of needs assessment data identified nine (9) critical needs, which were grouped into two "goal groupings:" Medical Care Issues (four critical needs) and Case Management Issues (five critical needs). Planning input and suggested ideas on the Medical Care Issues were obtained from members of the Guam medical community and stakeholders. Similarly, input and suggested ideas on the Case Management Issues were obtained from PLWHA and social service providers. For each critical need, this input has been organized under the following headings: Existing Resources, Challenges/Barriers, and Recommendations for action.

#### **Medical Care Issues (Critical Needs)**

- C. Medical Treatment (General)
- D. Medical Information, Consultation and Training on Patient Care
- E. Medical Treatment (Confidentiality)
- F. Medical Needs (late stage)

#### **C. Medical Treatment (General)**

##### **Existing Resources**

- On Guam there are at least fifteen (15) physicians in private practice or at public agencies who have treated HIV/AIDS patients, or have been consulted as specialists on diagnosis/care questions by another doctor with HIV/AIDS patients. About half of these physicians are currently providing active care to persons living with HIV/AIDS (PLWHA) on Guam (i.e., others being consulted or having had former patients).
- The Guam Department of Public Health and Social Service (DPHSS) has three clinics for community health care services: DPHSS Central in Mangilao, the Southern Region Community Health Center (SRCHC) in Inarajan and the Northern Region Community Health Center (NRCHC) in Dededo. Of the eight (8) physicians, only three (3) handle HIV/AIDS patient care: one (1) infectious disease specialist, and two (2) National Health Service Corps doctors (family practice, and internal medicine/ pediatric specialist).



- DPHSS in Mangilao has Medical social workers at all three clinics as well as the the STD/HIV Prevention Program staff, who together offer referral services to People Living With HIV/AIDS (PLWHA). There are out-patient pharmacy services for eligible clients, without charge at DPHSS Central in Mangilao. Pharmacies at the SRCHC in Inarajan and the NRCHC in Dededo accept patients with private insurance, or through the Medically Indigent Program (MIP), and Medicaid. Both Centers offer a sliding fee, however, only Southern (SRCHC) accepts Medicare for medical visits.
- Medical Social Workers at the three DPHSS clinics refer PLWHA to the following programs: Medically Indigent Program (MIP), the AIDS Drug Assistance Program (ADAP), Aid to the Permanently and Totally Disabled, the Food Stamps, Cash Assistance, and Maternal Child Health (MCH) programs. Ryan White Title II Program provides drinking water, nutritional supplements, gas coupons, counseling and other quality-of-life-enhancing services to clients. The Title II Program is administered by the STD//HIV Prevention Program under the Bureau of Communicable Disease Control.
- Central Public Health (Mangilao) and SRCHC (Inarajan) pharmacies dispense medications to PLWHA, and there are agency pharmacies for in-patient and eligible client needs at the Guam Memorial Hospital (GMH) and the Department of Mental Health and Substance Abuse (DMHSA).
- PLWHA are able to obtain counseling at the DMHSA for substance abuse issues and other mental health concerns. However, to date PLWHA have only sought DMHSA counseling for substance abuse issues, and this needs assessment did not hear of any one giving their HIV/AIDS status to be one of their presenting conditions.
- PLWHA who have reached a late stage of the disease may be admitted to the GMHA Acute Care facilities (associated with the Medical Surgical Ward). When referred, there are those who may go to the GMHA's Skilled Nursing Unit (SNU) in Barrigada. The SNU provides care for clients who require specialized care needs. Eligibility requires a physician's referral, and assessment by the SNU doctor for rehabilitation care (e.g., pain management, antibiotic long term care, physical therapy, etc.)
- On-island private laboratories and pharmacies provide ancillary services to PLWHA who either have insurance or the ability to self pay (i.e., the under-insured and un-insured). In addition, private clinics on-island, and HMOs offer health care services and education to PLWHA who have insurance or the ability to self pay. Off-island pharmacies, for example CVS ProCare, offer direct links to clients for information and access to medications.
- Private in-home health care services are available for those who have insurance or the ability to self pay. Isla Home Health Care, Guam Nursing Services, Paradise Home Care, and PacificCare Home Health are local companies on Guam that offers these services. For the underinsured and un-insured, DPHSS nurses at the primary health care centers DPHSS Community Health Nursing services can assist with non-invasive medical procedures, client and family assessment, education, and referral.
- At least three local insurance companies cover HIV/AIDS care on Guam, with varying levels of insurance coverage for PLWHA depending on the particular insurance plan they have with their insurance company.

## Challenges/Barriers

- Access to affordable health care is a barrier in receiving basic care needed by PLWHA clients. Affordable health care is not within financial reach of many clients. Sources of financial assistance need to be explored, such as the Ryan White CARE Act Title II programs, Medical Indigent Program (MIP) and Medicaid at DPHSS.
- Delayed Treatment: Too many PLWHA do not obtain HIV/AIDS services on Guam until they are symptomatic or in late stages of the disease. By this time many services and some treatment strategies may not be effective. Early case management of HIV+ individuals is needed to initiate medical and other health care program services (e.g., nutrition education, life-style health education, mental health counseling,) which will assist improving the individual's quality of life, and minimize the spread of HIV infection.
- Mental Health Services: PLWHA "anger" and emotional issues are a challenge and barrier. These psycho-social co-factors are amplified in some PLWHA by substance abuse problems. Doctors have experienced highly emotional and angry behavior as PLWHA attempt to cope with health symptoms, treatments, medications and their side effects. Doctor-patient health care relations are hampered by the lack of mental health services and resources to handle these psycho-social challenges for physicians.
- Language and Communication Barriers: Guam has PLWHA from various Asian-Pacific Islander ethnic groups who need interpreters in clinic settings to help translate physician information regarding their medical regimen (i.e., treatment plans, medication adherence and side effects) and reasons why they are given medications.
- Communication challenges also involve PLWHA who find it difficult to inform their physician that they have not adhered to or been compliant with medications. When the doctor orders lab work to measure the impact of medications and treatment efforts, this communication issue can complicate the patient-doctor relationship.
- Delayed Lab Results: There have been problems obtaining lab results in a timely manner. This makes it difficult for physicians to evaluate and diagnose patients.
- Medication compliance, adherence to treatment schedules, and time management: Serious challenges complicating the relationships between PLWHA and their physician (and medical social worker) is that some PLWHA are irregular in keeping appointments. Others do not adhere to their treatment plan (i.e., poor adherence to food requirements for medicines due to loss of appetite, irregular compliance with scheduled medicines, lack of rest, etc.).
- Lack of oral health care information: Many PLWHA have degenerative oral conditions. These are a result of opportunistic infections, gum disease, and lack of appropriate oral hygiene care specific to PLWHA.
- Lack of nutritional/herbal supplement interventions: Many physicians tend to overlook prescribing complimentary natural therapies addressing lifestyle behaviors and dietary practices known to effect the body's immune systems and shown to treat many AIDS related symptoms. These include nutritional and herbal supplement interventions.



- Lack of alternate therapy programs: Guam lacks progressive, alternative therapy programs to help PLWHA find sources of comfort and positive validation. Such interventions might include pet or horticultural therapies, massage, aromatherapy, and spirituality exploration. This will increase holistic care and alternative treatment therapies that may be culturally appropriate.
- Substance abuse issues: Many PLWHA will not admit to having substance abuse needs, yet even when they do, there are no programs specific to PLWHA at the Department of Mental Health and Substance Abuse, nor available at Guam's community non-government organizations (NGOs).
- Limited funding, and reduced staff work-hours at all HIV service providers severely hamper case management and service care coordination. No case management positions or program specifically funded for PLWHA currently exist in public agencies or at Guam's community non-government organizations (NGOs).
- DPHSS STD HIV office only has an 8am-5pm hotline for information, referrals, and supportive counseling. There is no 24 hour "warmline" where a person is "on-call" staffing a phone number to give out needed information, referrals and supportive counseling.

### **Recommendations (C)**

- The Guam Medical Society, and other professional societies (i.e., nurses, dentists and pharmacists) should network with the DPHSS Bureau of Communicable Disease Control's STD/HIV Program, and Medical Social Service Unit to develop case management protocols to increase the number of persons testing HIV positive who receive follow-up counseling with continuing coordinated care.
- The DPHSS Bureau of Communicable Disease Control, should work through the CPG/ AIDS Care Advisory subcommittee to actively create working relationships to benefit PLWHA. This may include nutritional and medical social services programs at DPHSS, GMH, and private health service providers at PacifiCare and the SDA Wellness Center to develop collaborative protocols increasing case management of early intervention services that address needs such as oral health care information, complimentary natural therapies addressing lifestyle behaviors and dietary practices known to effect the body's immune systems, and progressive and effective alternative therapies and programs.
- The AIDS Drug Assistance Program (ADAP) is still seriously under-funded. Guam Department of Public Health and Social Services (DPHSS) must continue to pursue increased funding to allow more PLWHA to benefit from ADAP.
- Guam pharmacies do not always have adequate supplies of HIV specific medications. These medications have a short shelf life. Local non-government, community-based organizations, like Coral Life Foundation (CLF) and GUAHAN Project (Guam AIDS HIV AIDS Network), and DPHSS ADAP program, should work with national organizations such as HRSA, the Asian & Pacific Islander Wellness Center, and the pharmaceutical compassionate programs to:

- increase the capacity of PLWHA to purchase medications on-line and off-island at discount rates.
  - negotiate for the best drug-pricing for anti-retroviral drugs to benefit all PLWHA, the insured, under-insured and un-insured (i.e., a One-Stop).
- Providers of services to PLWHA should be trained with the skills and sensitivity to engage clients at their current level of need. Services should be provided in a user friendly, individualized, non-judgmental manner, in places where clients feel comfortable.
- Local non-government, community-based organizations, like Coral Life Foundation, Dream for a Cure, GUAHAN (Guam AIDS HIV AIDS Network), and/or Guam's American Red Cross, should advocate for a seamless progression and participation of case management between stages of the disease (e.g., from early to late stages).
- The Bureau of Communicable Disease Control (BCDC) Title II ADAP program, DPHSS, should work through the CPG/AIDS Care Advisory subcommittee to produce an HIV/AIDS treatment "flow chart," similar to an immunization "shot record," that lists the patient's lab work (i.e., viral load and t-cell counts), medication list, opportunistic infections, and any recent hospitalizations, so they can share this information between various primary care providers, on and off-island.
- The Bureau of Communicable Disease Control (BCDC) Title II ADAP program, DPHSS, should work through the CPG/AIDS Care Advisory subcommittee to produce an HIV/AIDS treatment and resource directory to present the latest in medications and treatments for HIV/AIDS. New anti-retroviral therapies are slow to reach doctors on Guam. This directory should also provide PLWHA information of treatment options available not only on Guam and the United States, but also resources available from Australia, Japan and the surrounding region.
- The BCDC's Title II ADAP Program, DPHSS should work through the CPG/AIDS Care Advisory subcommittee to sponsor workshops involving PLWHA that can help doctors know what alternative healing therapies are being used by patients on Guam. These would be opportunities for CME training by off-island experts for PLWHA to learn which kinds of alternative or traditional therapies for pain cessation have some kind of research support.
- The BCDC's Title II ADAP program, DPHSS, should begin inquiries and discussions to search for possible research opportunities where Guam could be included as a site for participation in HIV clinical trials research. This would be a strategy for overcoming the barrier that new anti-retroviral therapies are slow to reach doctors on Guam, and it would provide an access mechanism to the latest in medications and treatments for HIV/AIDS pending FDA approval (to those PLWHA who might qualify to be participating subjects). Clinical trial research can be encouraging to clients who have become resistant to medications or who do not respond favorably to existing medications. Discussions and inquiries could begin with the Guam Medical Society (to involve local physicians interested in research) and the Pacific AIDS Education and Training Center (PAETC), the Hawai'i AETC, as part of the John A. Burns Medical School. Contact should also be made with the Pacific Island Jurisdiction AIDS Action Group (PIJAAG) and its resource contacts at the Asian &



- Pacific Islander Wellness Center, and the Asian & Pacific Islander American Health Forum, in San Francisco, CA.
- The Bureau of Primary Care Services, DPHSS should apply for the Early Intervention Services (EIS) grant funding that will cover primary care services for medical, dental, and case management and other related services.

#### **D. Medical Information and training on patient care**

##### **Existing Resources**

- The Pacific AIDS Education and Training Center (PAETC), one of the national regional centers funded by the Health Resources and Services Administration under the Ryan White CARE Act, provides AIDS-related training, education and information services to health care providers. It has 15 local sites in several western states, including Hawai'i. The Hawai'i AETC, part of the John A. Burns Medical School, with PAETC assistance has been engaged in a project to support primary care in the Pacific Island region and increase the capacity of doctors and nurses in the region to manage HIV disease. A number of training events have been conducted since the project began in 2000. Two region-wide week long clinical HIV conferences were held for 2-3 selected doctors and nurses from each of the US affiliated jurisdictions. The first Conference was held in Guam with the assistance of the DPHSS, Coral Life Foundation and SDA clinic for 18 doctors and nurses. The second Conference was held in Honolulu for 27 doctors and nurses. A third HIV Clinical Conference is planned for May 4-8 in Honolulu.
- Consultation/training visits have been made to each jurisdiction by a team including an HIV physician, nurse.
- All participants, 27 doctors and nurses have been offered and completed week-long mini-residencies with HIV physicians and nurses either in Hawaii or California. Two doctors and a DPHSS nurse from Guam each spent a week at HIV clinical training sites.
- In addition, over the past three years HAETC has offered individual physicians clinical consultation by phone from HIV physicians in Hawaii and in California.
- Since 2002, using PEACESAT telecommunication system there have been HIV Case Conference presentations every two months available for all jurisdictions. So far Chuuk, CNMI, and American Samoa have presented cases. During the February teleconference the nurses of the regional APNLC attended. The University of Guam PEACESAT station has assisted linking Guam participants with these sessions and received support from the HAETC.
- As of January 1, 2003, the HAETC has supported an HIV training sub-site in Chuuk. The goal of the subsite is to train health care providers in Chuuk and eventually throughout FSM in HIV medicine.
- Other support activities include providing computers and printers for jurisdictions-in-need so that HIV internet resources can become available.
- There are plans to send Dr Amy Kindrick to Guam in June, 2003 to provide HIV clinical case consultation to physicians and nurses.

- HAETC will continue to support HIV clinical care by offering selected training and training related support to HIV medical personnel. This project currently has funding through June, 2005.
- The HAETC project has also initiated planning (April, 2002) for a Local Performance Site (LPS) to be located somewhere in the Pacific island jurisdictions (Guam site visit September 2002). The LPS development will be a three year process.
- The Guam AYUDA Foundation has been contracted by HAETC (January 2003) to facilitate and manage logistics for getting medical training, information materials and medical supplies to the physicians and health care providers working with HIV/AIDS patients in the island state of Chuuk, Federated States of Micronesia.
- Guam Memorial Hospital Authority (GMHA) Education Department coordinates health education to the healthcare providers, patients and their families on Guam and from the islands of Micronesia. GMHA is an accredited Continuing Medical Education (CME) provider for Category I activities through the Hawaii Medical Association, and an approved Continuing Education (CE) provider for nursing education by the California Board of Nursing. GMHA coordinates the monthly Guam Medical Society CME presentations at hotel venues. Distance Education/Tele-CME activities are conducted in partnership with the University of Guam's Telecommunications/Distance Education Division (i.e., the PEACESAT station), the University of Hawaii John A. Burns School of Medicine Internal Medicine Department, The UH Telemedicine Program and Castle Medical Center.
- The University of Guam's (UOG) Telecommunication and Distance Education (TADEO) division of the Center for Continuing Education and Outreach Programs is the Micronesian hub for the PEACESAT (Pan-Pacific Education and Communication Experiments by Satellite) Network, the high frequency radio (HF/SSB) hub and control point for Guam and Micronesian island communications. TADEO provides voice, data and fax communications among the islands as a public service. Daily programming is delivered every morning to the region and distance education courses and workshops are offered through the HF-SSB, microwave, and Internet servers at the UOG facility operation.
- The UOG College of Nursing and Health Sciences is committed to improving the health, fitness, personal and social well-being and social development of the people of Guam and the Western Pacific. To realize this mission the College of Nursing and Health Sciences delivers programs designed to prepare graduates for their professions and provides ongoing educational development for members of the respective professions. The College fosters collaboration among the disciplines and facilitates inter-professional education. It engages in collaborative research, and community service of students and faculty focused on the needs of the people of Guam and the Western Pacific.
- The Office of Minority Health (OMH): Resource HIV Education and Training Center, in San Francisco, CA, offers technical assistance and training. It is willing to assist Guam with training needs for AIDS Care advisory councils and community planning groups. The Guam Ryan White Needs Assessment Advisory Council identified capacity building for advocacy on medical care and the development of hospice services as a training priority.



- Pacific Island Jurisdiction AIDS Action Group (PIJAAG) was formed by representatives of the six Pacific Island jurisdictions including AIDS directors; public health program staff, community stakeholders, as well as US-Centers of Disease Control funded capacity-building assistance providers; the Asian & Pacific Islander Wellness Center, and the Asian & Pacific Islander American Health Forum. The group's mission is to advocate for the provision of quality HIV/AIDS prevention and care services in the region, advise national, international, and local policy entities on HIV/AIDS, and to strengthen and coordinate AIDS activities through the sharing of information and resources within the region.

### Challenges/Barriers

- Physicians, and the multidisciplinary team of health care providers, who treat patients would like to have more access to information and consultation as they work with PLWHA patients to provide the best health care service possible. A team approach in treating this disease is needed to pull from existing resources and information sources. This team approach can also identify gaps in delivery of treatments to patients. This will help achieve this plan's vision for a continuum of care services.
- Understanding side effects and education of HIV/AIDS medications and articulating them to clients is very much needed. Knowledgeable doctors(s) specializing in HIV/AIDS are needed, as well as access to medical information and consultation.
- Most of the island's community of health care professionals and physicians are not aware of the Pacific AETC or the Hawai'i AETC, and most are not benefiting from these educational, telemedicine and consultation resource services.
- Language barriers prevent appropriate health care services to be properly delivered. This is a complex problem because merely having a family member or friend as an interpreter is not a solution. For example, loss of confidentiality and conflict of interest when a family member or friend is the interpreter (see Case Management Recommendations).
- Cultural barriers may affect how services are delivered and to whom. For example, it may be difficult for a client to ask for help because of pride and shame instilled by one's culture.
- For Micronesian Islander HIV/AIDS patients in particular, gender barriers affect acceptable treatment methods for PLWHA. For example, a spouse or parent may refuse treatment to be administered to their family member unless given by specifically a male or a female individual.
- Social barriers include the perceived stigma, shame and guilt of being HIV positive. Moreover, there exists great cultural variation in the social barriers across all the different Asian and Pacific Island ethnic groups seeking care services on Guam. Such differences even exist between different island groups within each island jurisdiction.
- Lack of family support is evident where families do not fully understand the HIV/AIDS epidemic and the impact it has on the client. Some families reject the client due to fear and ignorance of HIV/AIDS, or the client's co-existing issues (e.g., drug and alcohol abuse and mental health issues). Many times, the way they were infected plays a role in determining their rejection by their families. Many clients then find themselves living from home to home with friends, relatives and acquaintances for short periods of time.



- The establishment and development of case management programs requires training of existing social service workers to produce a pool of knowledgeable case managers who possess a strong understanding of HIV/AIDS. This type of training curriculum should also be extended to train health and social service professionals specifically in the delivery of services to PLWHA.

### **Recommendations (D)**

- The Guam HIV Prevention CPG subcommittee group should contact the OMH: Resource HIV Education and Training Center, in San Francisco, CA, to request training and technical assistance to help them advocate for these recommended actions.
- The Guam HIV Prevention CPG subcommittee group, GMHA Education, and UOG CCEOP/PEACESAT should work with regional associations like PIJAAG Pacific Island Health Officers Association, (PIHOA) to adapt the training needs identified in the various sections of this plan into formal regional requests to HAETC/PAETC for training and telemedicine conferences. The aim is to increase the number of Guam and regional physicians and health care providers benefiting from AETC educational and consultation services. Requests for case management training should be included for the development of case management services (refer to case management need recommendations). Submissions to HAETC/PAETC can include requests for telemedicine and distance education equipment to facilitate and expand these services as needed.
- The GMHA Education Department should devote a certain number of Grand Rounds to HIV/AIDS care presentations, and UOG College of Nursing and Health Sciences should work with the HAETC to develop their curriculum to produce knowledgeable nurses and case managers who possess a strong understanding of HIV/AIDS. The development of the University's nursing curriculum should also include practicum experiences with HIV/AIDS primary care on island (e.g., the SRCHC, MSS and other DPHSS programs, as well as island clinics).
- The DPHSS AIDS Drug Assistance Program should inform and increase awareness of the "Prutehi Hao" website, and the Ryan White CARE Act programs among Guam's health care professionals and health educators. The Prutehi Hao website resource should be expanded to include upcoming CME training in its "Events Calendar," more enhanced links to the most recent medical information on HIV/AIDS.
- Local non-government, community-based organizations, like Coral Life Foundation, Dream for a Cure, GUAHAN (Gua[m] HIV AIDS Network) Project, and/or American Red Cross Guam Chapter, should develop an educational curriculum for giving newly diagnosed HIV+ clients a basic presentation of what HIV is and what it is not. This curriculum should be made available to doctors and case managers so they can give presentations to clients on a regular basis and parallel the progression of the HIV stages in the client. The client will know what to expect and why changes are happening to their bodies. These presentations should also be given to families and caregivers.

## **E. Medical Treatment (Confidentiality)**

### **Existing Resources**

- Guam has consent forms at DPHSS, GMHA and clinics that assure client confidentiality for HIV Anti-body Testing and Counseling. These forms are signed by the client and the doctor or counselor.
- All HIV testing must be preceded by informed consent with the client and doctors or counselor.
- The DPHSS Guam Community Health Centers, as well as all Government of Guam agencies (e.g., GMHA, etc.) have reviewed procedures to protect patient health information and ensure patient privacy and confidentiality as mandated by the Health Insurance Portability and Accountability Act (HIPPA) of 1996 (Effective April 2003). Federal HIV confidentiality regulations and requirements apply to all recipients of U.S. Federal grant funding, including community-based AIDS non-profit organizations.

### **Challenges/Barriers**

- There are no local laws or legislation that protects confidentiality of HIV test results.
- Guam still uses a “name-based” identifiers for all HIV/AIDS surveillance and data collection. Current lab practices, and pharmacy prescripts still include client names for HIV specific medications and services.
- Confidentiality is too often compromised and not ensured. When client confidentiality is breached, no one is held accountable.
- Guam’s small size and close-knit community can be a barrier to preserving confidentiality, even among caregivers. For this reason, some clients access help from off-island sources only.
- Disclosure of HIV status is needed to confirm eligibility of services (e.g., disability and ADA etc.) for PLWHA. When the PLWHA has been diagnosed off-island and thus may not have a Guam-base medical social worker, documentation of HIV/AIDS diagnosis can be a challenge for intake and screening for some public social services (GMHA, DPHSS, DISID, DMHSA).
- There is social and political pressure against confidentiality due to the fact that many people on Guam and through out the region believe that identities of PLWHA’s must be made public to prevent HIV/AIDS from spreading.
- Some physicians in the Micronesian Islands do not maintain client confidentiality of PLWHA in their island states. This has contributed to in migration of PLWHA to Guam seeking anonymity and confidence in the capacity of services to maintain confidentiality.
- Many PLWHA are not aware of their patient rights and privacy protections.

## **Recommendations (E)**

- Doctors, nurses, therapists, case managers, counselors, social workers, family members, insurance companies, support organizations and care givers must be trained to maintain client confidentiality even amongst themselves when they discuss cases. They should not assume that the identities of all PLWHA is known among this group. Client confidentiality must be maintained. When information must be shared or exchanged, it must be done discreetly and professionally.
- A coding system should be implemented to identify PLWHA's in order to protect client privacy, in the processing of their lab testing and medication purchasing. This coding system is needed to enable caregivers, physicians, and pharmacies to provide medications and treatments without revealing clients' names.
- Physicians, nurses, health care providers and family care givers should receive training in cultural sensitivity to augment their communication skills. This needs assessment found that when discussing issues of HIV/AIDS with other doctors, health care providers and family care givers, health care providers are not sensitive to the fact that they have colleagues who also have HIV/AIDS. Thus, such training can enhance the health care community's ability to effectively communicate amongst themselves in ways promoting the best health care possible on Guam.
- Local non-government, community-based organizations, like Coral Life Foundation (CLF) and GUAHAN Project (Guam AIDS HIV AIDS Network), and DPHSS ADAP program, should educate PLWHA and care givers on their individual rights for confidentiality and privacy issues.

## **F. Medical Needs (late stage)**

### **Existing Resources**

- DPHSS in Mangilao has Medical social workers at all three clinics as well as the the STD//HIV Prevention Program staff, who together offer referral services to People Living With HIV/AIDS (PLWHA). There are out-patient pharmacy services for eligible clients, without charge at DPHSS Central in Mangilao. Pharmacies at the SRCHC in Inarajan and the NRCHC in Dededo accept patients with private insurance, or through the Medically Indigent Program (MIP), and Medicaid. Both Centers offer a sliding fee, however, only Southern (SRCHC) accepts Medicare for medical visits.
- Medical Social Workers at the three DPHSS clinics refer PLWHA to the following programs: Medically Indigent Program (MIP), the AIDS Drug Assistance Program (ADAP), Aid to the Permanently and Totally Disabled, the Food Stamps, Cash Assistance, and Maternal Child Health (MCH) programs. Ryan White Title II Program provides drinking water, nutritional supplements, gas coupons, counseling and other quality-of-life-enhancing services to clients. The Title II Program is administered by the STD//HIV Prevention Program under the Bureau of Communicable Disease Control



- Central Public Health (Mangilao) and SRCHC (Inarajan) pharmacies dispense medications to PLWHA, and there are agency pharmacies for in-patient and eligible client needs at the Guam Memorial Hospital (GMH) and the Department of Mental Health and Substance Abuse (DMHSA).
- PLWHA are able to obtain counseling at the DMHSA for substance abuse issues and other mental health concerns. However, to date PLWHA have only sought DMHSA counseling for substance abuse issues, and this needs assessment did not hear of any one giving their HIV/AIDS status to be one of their presenting conditions.
- PLWHA who have reached a late stage of the disease may be admitted to the GMHA Acute Care facilities (associated with the Medical Surgical Ward). When referred, there are those who may go to the GMHA's Skilled Nursing Unit (SNU) in Barrigada. The SNU provides care for clients who require specialized care needs. Eligibility requires a physician's referral, and assessment by the SNU doctor for rehabilitation care (e.g., pain management, antibiotic long term care, physical therapy, etc.)
- On-island private laboratories and pharmacies provide ancillary services to PLWHA who either have insurance or the ability to self pay (i.e., the under-insured and un-insured). In addition, private clinics on-island, and HMOs offer health care services and education to PLWHA who have insurance or the ability to self pay. Off-island pharmacies, for example CVS ProCare, offer direct links to clients for information and access to medications.
- Private in-home health care services are available for those who have insurance or the ability to self pay. Isla Home Health Care, Guam Nursing Services, Paradise Home Care, and PacifiCare Home Health are local companies on Guam that offers these services. For the underinsured and un-insured, DPHSS nurses at the primary health care centers DPHSS Community Health Nursing services can assist with non-invasive medical procedures, client and family assessment, education, and referral.
- There are at least three local insurance companies that cover some HIV/AIDS care on Guam. For the late stage of illness, **the three provide hospice coverage** (\$50/day for medications, care and equipment), except Guam does not have a hospice.
- Several community-based, non-government organizations (NGOs) provided food, clothing, housing and transportation assistance to persons in need, including PLWHA. Catholic Social Services (CSS) offers provides food baskets, clothing and offers assistance to homeless individuals. The Salvation Army offers emergency housing and life skills for clients. The Red Cross provides assistance to PLWHA in times of emergency and also provides basic HIV/AIDS information to the public. The Santa Barbara Church in Dededo and St. John's Church in Tumon have documented cases of directly assisting PLWHA with transportation, food and temporary shelter.

### Challenges/Barriers

- Currently there is no hospice facility on Guam. This kind of service function is needed to provide a place where clients can spend their last days in dignity
- There also is no operational respite care service or facility.

- The absence of sources of financial assistance and insurance coverage for medications, nursing care, and equipment during end/late stage of the illness are a serious challenge. This challenge also includes lack of respite care and insurance coverage.
- Basic housekeeping services are not always readily available for PLWHA clients who may need it and have the resources to cover such expenses.
- Awareness and knowledge of the referral process for GMHA Skilled Nursing Unit (SNU) in Barrigada and other services is a barrier limiting access by PLWHA clients.
- Training of health care professionals to honor patient wishes with compassion and conscientiousness.
- The lack of case management services to organize coordinated multi-disciplinary teams of service providers (family physician, home care nursing, respite care, legal aid, pharmacies, insurance/Medicaid, mental health and spiritual) with at least one case manager designated the lead to ensure that all care services for the individual/family are integrated and achieved.
- Service provider and community perceptions of AIDS death and dying are based on stigma and fear, and services are not always compassionate. Education of all late stage service providers (and the community) is required to overcome these perceptions as one way to begin to make services more client-centered.

### **Recommendations (F)**

- Local non-government, community-based organizations, like Coral Life Foundation (CLF) and GUAHAN Project (Guam AIDS HIV AIDS Network), and DPHSS ADAP program, should network with national organizations such as HRSA, the Asian & Pacific Islander Wellness Center, and the pharmaceutical compassionate programs to:
  - increase the capacity of PLWHA to purchase medications on-line and off-island at discount rates.
  - negotiate for the best drug-pricing for anti-retroviral drugs to benefit all PLWHA, the insured, under-insured and un-insured (i.e., a One-Stop).
- The Guam HIV/AIDS Care Advisory Council, a subcommittee of the HIV Prevention CPG (refer to General Issue recommendations) should collaborate with agencies and community based NGOs who are addressing the island's need for hospice facilities/respite care programs. In this way, if any hospice or respite care facilities are developed on Guam, they will become an option for PLWHA.
- Local non-government, community-based organizations, like CLF, Dream for a Cure, GUAHAN, and/or Red Cross, can then advocate to establish guideline criteria for home care services for PLWHA in their late stages. These would also apply to hospice services, if they are eventually developed on-island. The guidelines should include criteria in determining the quality of life issues in a patient's remaining days.
- GMHA Education Department should work with the Pacific and Hawaii AETC to provide guidance and training for health care workers and physicians on how to address the psychosocial needs of patients as they progress into the late stages of living with AIDS.

- Providers of services to PLWHA and family/care givers should undergo cultural sensitivity training to obtain communication skills to engage clients during the late stage of illness. Services should be provided in a user friendly, individualized, non-judgmental manner, and in places where clients feel comfortable.
- The Guam HIV/AIDS Care Advisory Council, a subcommittee of the HIV Prevention CPG and Guam Legal Services should conduct a Title II consortia conference to help service providers develop their practices to more effectively address PLWHA needs for estate planning, survivor benefits, wills, home-care, and other late-stage care issues.

## **Guam HIV/AIDS Care Plan: Case Management Issues**

Critical Needs, Existing Resources, Challenges/Barriers, and Recommendations

### **Case Management Issues**

- G Case Management Needs (Service Coordination, Information, and Referrals)
- H. Case Management Needs (Daily life and Housing Assistance)
- I. Educational Issues and Information Needs of PLWHA & Caregivers
- J. Psycho-social Need Issues (Mental Health)
- K. Financing Medical Costs

### **A. Case Management Needs (Service Coordination, Information, and Referrals)**

#### **Existing Resources**

- DPHSS in Mangilao has Medical social workers at all three clinics as well as the the STD/HIV Prevention Program staff, who together offer referral services to People Living With HIV/AIDS (PLWHA). There are out-patient pharmacy services for eligible clients, without charge at DPHSS Central in Mangilao. Pharmacies at the SRCHC in Inarajan and the NRCHC in Dededo accept patients with private insurance, or through the Medically Indigent Program (MIP), and Medicaid. Both Centers offer a sliding fee, however, only Southern (SRCHC) accepts Medicare for medical visits.
- Medical Social Workers at the three DPHSS clinics refer PLWHA to the following programs: Medically Indigent Program (MIP), the AIDS Drug Assistance Program (ADAP), Aid to the Permanently and Totally Disabled, the Food Stamps, Cash Assistance, and Maternal Child Health (MCH) programs. Ryan White Title II Program provides drinking water, nutritional supplements, gas coupons, counseling and other quality-of-life-enhancing services to clients. The Title II Program is administered by the STD//HIV Prevention Program under the Bureau of Communicable Disease Control.
- Central Public Health (Mangilao) and SRCHC (Inarajan) pharmacies dispense medications to PLWHA, and there are agency pharmacies for in-patient and eligible client needs at the Guam Memorial Hospital (GMH) and the Department of Mental Health and Substance Abuse (DMHSA).



- PLWHA are able to obtain counseling at the DMHSA for substance abuse issues and other mental health concerns. However, to date PLWHA have only sought DMHSA counseling for substance abuse issues, and this needs assessment did not hear of any one giving their HIV/AIDS status to be one of their presenting conditions.
- PLWHA may apply for housing assistance with the Guam Housing and Urban Renewal Authority (GHURA). GHURA has Section 8 vouchers specifically for persons with disabilities, including PLWHA. Also, under Public Housing, GHURA has units' dedications to the elderly and persons with disabilities.
- Ryan White Title II Program provides drinking water, supplements, gas coupons, counseling and other quality-of-life-enhancing services to clients. The Title II Program is administered by DPHSS.
- PLWHA who have reached a late stage of the disease may be admitted to the GMHA Acute Care facilities (associated with the Medical Surgical Ward). When referred, there are those who may go to the GMHA's Skilled Nursing Unit (SNU) in Barrigada. The SNU provides care for clients who require specialized care needs. Eligibility requires a physician's referral, and assessment by the SNU doctor for rehabilitation care (e.g., pain management, antibiotic long term care, physical therapy, etc.)
- PLWHA are also able to access services from several non-government organizations (NGOs) that exist on Guam to help address HIV/AIDS needs of PLWHA. Catholic Social Services (CSS) offers assistance to homeless individuals, food baskets and clothing to PLWHA. The Salvation Army offers emergency housing and life skills for clients. The Red Cross provides assistance to PLWHA in times of emergency and also provides basic HIV/AIDS information to the public.
- The Santa Barbara Church in Dededo and St. John's Church in Tumon have documented cases of directly assisting PLWHA with transportation, food and temporary shelter.
- Family and friend support is extremely important in many lives of PLWHA. This was identified as an integral part of coping with an HIV/AIDS diagnosis. Support and care is vitally important at the family level.
- Supportive legislators offer limited support within their scope and resources. Guam's culture enables this relationship to exist between people and local government leaders. These leaders are very accessible and provide support or material contributions to PLWHA who approach them. This is a form of local social reciprocity that is part of living on Guam.
- The Guam HIV Community Planning Group (CPG) identifies entities and organizations that offer services related to HIV/AIDS on Guam. While not a comprehensive resource directory, the CPG Plan can be used as a source reference for PLWHA.

## Challenges/Barriers

- Lack of transportation to the Guam Memorial Hospital (GMH) Skilled Nursing Unit (SNU) in Barrigada is a barrier limiting access by clients.
- Cultural considerations and value systems for risk behaviors include topics that are taboo and unpopular for PLWHA to discuss openly with caregivers and family members. There is discomfort in discussing sexuality and drug injection use. There is resistance among PLWHA in discussing infidelity issues, multiple sex partners, and using alternative treatments for HIV/AIDS, such as smoking marijuana for medicinal purposes.
- Communication barriers include language differences, no provisions for the hearing-impaired community, lack of public announcements or public information routes, and literature that may be outdated and obsolete.
- Limited funding at all HIV service providers severely hampers service coordination efforts and compiling of information for dissemination to clients.
- Lack of AIDS specific community-based organizations (CBO) on Guam causes clients to “fall through the cracks” of the service providers network. Such CBO are better equipped to maintain contact with clients that need care and services.
- No case management positions or program specifically funded for PLWHA currently exist in public agencies or CBO.
- Non-Existent HIV/AIDS-specific CBO on Guam means that clients do not have a place to gather for support and advocacy. This is a large gap in the total service delivery system.
- Transportation for clients and caregivers is a critical issue. Fuel, auto insurance and maintenance costs are very high. Many PLWHA no longer can afford to own or operate a vehicle. Public transportation is limited, inconvenient, has limited hours of operation, and is unreliable. Taxis are extremely expensive. It is not practical to walk due to the heat, rain, stray dogs, bad drivers, lack of sidewalks and crosswalks, and terrain of the island.
- The Catholic Church on Guam is a barrier for Catholics living with HIV/AIDS. Some clients and individuals at-risk for HIV infection are at odds with Catholic Church doctrines of no premarital sex, no condom use, no artificial contraception and no homosexual practices. The Catholic Church has refused distribution of local HIV/AIDS informational material on church grounds produced by both the federal government and local community-based organizations. The church currently seems to have little interest in the advocacy of PLWHA.
- Currently no available hospice program exists to provide a place where clients can spend their last days in dignity.
- Substance abuse issues are often overlooked for PLWHA with this need. Many PLWHA will not admit to having substance abuse needs because dealing with the enormity of their HIV/AIDS status is already overwhelming. There are no programs specific to PLWHA with the Department of Mental Health and Substance Abuse.
- Lack of family support is evident where families do not fully understand the HIV/AIDS epidemic and the impact it has on the client. Some families reject the client due to fear and ignorance of HIV/AIDS. Many clients then find themselves living from home to home with friends, relatives and acquaintances for short periods of time. Many times, the way they were infected plays a role in determining their rejection by their families.
- Lack of empowerment of PLWHA prevents them from realizing their full potential as productive, contributing members of the community. Empowerment can bring enhanced quality of life to PLWHA.

- Lack of organized support groups for PLWHA and their families mean that support and communication that can benefit them are not realized. Linkages to volunteers and CBOs may not be made if such groups do not exist.
- DPHSS STD HIV office has a 24-hour hotline for information only but is unable to provide information, referrals, and supportive counseling. There is no “warm line” where there will always be a real person staffing the phone line to give out needed information, referrals and supportive counseling.
- There is no political lobbying body for HIV/AIDS issues. This means that the voices of PLWHA are not heard when formulating regulations and legal policies that directly affect the services and access to care.
- Confidentiality is too often compromised and not ensured. When client confidentiality is breached, no one is held accountable.
- Access to affordable health care is a barrier in receiving basic care needed by clients. Affordable health care is not within reach of many clients.
- Lack of housing for PLWHA and families as a result of long waiting lists at GHURA often discourages other PLWHA and their families from seeking the same services.
- PLWHA without a permanent residence, who move from place to place, are difficult for follow-ups and home visits.
- Confusing system of care for HIV/AIDS services currently in place changes constantly and this becomes a barrier in information dissemination to clients.
- The community is unaware of the impact HIV/AIDS has on the island. The public has largely ignored HIV/AIDS awareness. This means that the public has no interest in learning about the needs of the HIV/AIDS community. There must be a vested interest in HIV/AIDS within the community.

### **Recommendations (G)**

- Pacific Islands Jurisdiction AIDS Action Group (PIJAAG) participation and involvement must include representatives from Guam to improve communication and service delivery between programs, both private and public, to ensure that needs of PLWHA are met.
- Linkages must be established to work with the Asian Pacific Islander American Health Forum (APIAHF) and the Asian and Pacific Islander Wellness Center (APIWC) to help develop policies in the health care delivery to PLWHA.
- There must be consistent and quality service delivery so that all clients are treated fairly and equally.
- More public awareness of HIV/AIDS through education and community events will eradicate some misinformation about HIV/AIDS.
- Engage all churches of all denominations to better understand people living with HIV/AIDS on Guam.
- DPHSS to pursue Early Intervention Services (EIS) and Ryan White Title II & Title III funding. GHURA to pursue discretionary funding under Housing Opportunities for People With AIDS (HOPWA).
- The Government of Guam must fund programs for HIV/AIDS-specific needs and services.
- Develop a centralized facility for HIV/AIDS resources available 24-hours a day.
- Develop a multi-agency plan to assist homeless clients living with HIV/AIDS.



- Mechanisms must be in place to make the government accountable and answerable for making this proposed case management program work for everyone, including clients that are in marginalized communities.
- HIV/AIDS community-based organizations such as the GUAHAN Project should apply for grant money in collaboration with GHURA to address issues such as housing for PLWHA who are homeless or are seeking housing assistance.
- A vibrant AIDS Advisory Group and a vigorous Guam HIV Community Planning Group (CPG) are needed to identify available services with action steps to resolve service delivery voids. Empower PLWHA and their families to advocate for improvements to the System of Care Services for clients. (See General Recommendation A: Continued Community Advisory Involvement)

## **H. Case Management Needs (Daily Life and Housing Assistance)**

### **Existing Resources**

- There are community-based, non-government organizations (NGOs) on Guam delivering social services which help address needs of PLWHA. Catholic Social Services (CSS) offers assistance to homeless individuals, food baskets and clothing to PLWHA. The Salvation Army offers emergency housing and life skills for clients. The Red Cross provides assistance to PLWHA in times of emergency and also provides basic HIV/AIDS information to the public. The Ayuda Foundation has provided clients with equipment such as wheelchairs.
- DPHSS in Mangilao has Medical social workers at all three clinics as well as the the STD/HIV Prevention Program staff, who together offer referral services to People Living With HIV/AIDS (PLWHA). There are out-patient pharmacy services for eligible clients, without charge at DPHSS Central in Mangilao. Pharmacies at the SRCHC in Inarajan and the NRCHC in Dededo accept patients with private insurance, or through the Medically Indigent Program (MIP), and Medicaid. Both Centers offer a sliding fee, however, only Southern (SRCHC) accepts Medicare for medical visits.
- Medical Social Workers at the three DPHSS clinics refer PLWHA to the following programs: Medically Indigent Program (MIP), the AIDS Drug Assistance Program (ADAP), Aid to the Permanently and Totally Disabled, the Food Stamps, Cash Assistance, and Maternal Child Health (MCH) programs. Ryan White Title II Program provides drinking water, nutritional supplements, gas coupons, counseling and other quality-of-life-enhancing services to clients. The Title II Program is administered by the STD//HIV Prevention Program under the Bureau of Communicable Disease Control.
- Central Public Health (Mangilao) and SRCHC (Inarajan) pharmacies dispense medications to PLWHA, and there are agency pharmacies for in-patient and eligible client needs at the Guam Memorial Hospital (GMH) and the Department of Mental Health and Substance Abuse (DMHSA).
- PLWHA are able to obtain counseling at the DMHSA for substance abuse issues and other mental health concerns. However, to date PLWHA have only sought DMHSA counseling for substance abuse issues, and this needs assessment did not hear of any one giving their HIV/AIDS status to be one of their presenting conditions.

- The Division of Integrated Services for Individuals with Disabilities (DISID) offers limited services to PLWHA.
- Guam Legal Services offers support in client issues such as discrimination, custody disputes, estate planning and adoption.
- PLWHA may apply for housing assistance with the Guam Housing and Urban Renewal Authority (GHURA). GHURA has Section 8 vouchers specifically for persons with disabilities, including PLWHA. Also, under Public Housing, GHURA has units' dedications to the elderly and persons with disabilities.
- The different churches on Guam have been identified as sources of strength and healing for some PLWHA. Clients identified clergy members of some churches as supportive and caring.
- The Santa Barbara Church in Dededo and St. John's Church in Tumon have documented cases of directly assisting PLWHA with transportation supportive counseling and temporary shelter.
- A positive support system within the family is important and exists in some client families. This type of support is basic and contributes greatly to the well being of the client.
- Volunteers make up a large component of HIV/AIDS care delivery. Their contributions to client care are more informal and less regimented. This facilitates care outside a clinical setting and is very beneficial to clients.
- The Naval Hospital on Guam has provided services to military dependents, retirees, and eligible veterans living with HIV/AIDS.
- Cultural considerations and value systems for risk behaviors may include topics that are taboo and unpopular for PLWHA to discuss openly with caregivers and family members. There may be discomfort in discussing sexuality and drug injection use. There may be resistance discussing infidelity issues and multiple sex partners and using alternative treatments to HIV/AIDS such as smoking marijuana for medicinal purposes.

### **Challenges/Barriers**

- There is no centralized facility on Guam where PLWHA can access care, services and support in one place.
- The Catholic Church on Guam is a barrier for Catholics living with HIV/AIDS. Some clients and individuals at-risk for HIV infection are at odds with Catholic Church doctrines of no premarital sex, no condom use, no artificial contraception and no homosexual practices. The Catholic Church has refused distribution of local HIV/AIDS informational material on church grounds produced by both the federal government and local community-based organizations. The church seems to have little interest in the advocacy of PLWHA.
- Communication barriers include language differences, no provisions for the hearing-impaired community, lack of public announcements or public information routes, and literature that may be outdated and obsolete.
- Lack of other Community-Based Organizations (CBO) on Guam to address HIV/AIDS issues causes clients to "fall into the cracks". Such CBO are better equipped to maintain contact with clients that need care and services
- Non-Existent HIV/AIDS-specific CBO on Guam mean that clients do not have a place to gather for support and advocacy. This is a large gap in the total service delivery system.
- Transportation for clients and caregivers is a large issue. Fuel, auto insurance and maintenance costs are very high. Many PLWHA no longer can afford to own or operate a vehicle. Public transportation is limited, inconvenient, has limited hours of operation, and is unreliable.



- Substance Abuse issues are often not treated with HIV/AIDS as a co-factor and vice-versa. As a result substance abuse and HIV/AIDS are treated separately versus addressing them together with appropriate interventions.
- Lack of family support is evident where families do not fully understand the HIV/AIDS epidemic and the impact it has on the client. Some families reject the client due to fear and ignorance of HIV/AIDS. Many clients then find themselves living from home to home with friends, relatives and acquaintances for short periods of time. Often, the way they were infected plays a role in determining their rejection by their families.
- Lack of empowerment of PLWHA prevents them from realizing their full potential as productive, contributing members of the community. Empowerment can bring enhanced quality of life to PLWHA.
- Confidentiality is compromised and not ensured. When client confidentiality is breached, no one appears to be held accountable with appropriate consequences on Guam.
- Lack of trained professional caregivers specifically for PLWHA.
- Lack of time management guidance. This is needed to regulate nutrition intake due to loss of appetite, adherence to scheduled medicines, rest regulation, personal time management and appointment follow through with social workers and doctors.
- Lack of oral health care information. Many PLWHA have degenerative oral conditions. These are a result of opportunistic infections, gum disease, and lack of appropriate oral hygiene care specific to PLWHA.
- Basic housekeeping services are not always readily available for clients who may need it and have the resources to cover such expenses.
- Caregivers are not always trained to help PLWHA in more acute and specialized needs.
- There is a distinct lack of progressive and effective alternative therapies and programs to help PLWHA find sources of comfort and positive validation. Such interventions might include pet therapy, aromatherapy, spirituality exploration,
- There is no PLWHA speakers' bureau on Guam. This group of empowered PLWHA could be effective community teachers who use their HIV status as tools for HIV/AIDS prevention, education and awareness to benefit the community. This can also impart PLWHA with a sense of purpose and direction.

### **Recommendations (H)**

- A community collaboration between private and government agencies to establish a centralized location for service care delivery, support and resources for PLWHA is needed and PLWHA
- Community AIDS organizations such as GUAHAN Project should assign a person to conduct formal volunteer support program activities and organized community mobilization of volunteers
- There must be greater consumer and stakeholder involvement in the care giving process. Incentives will motivate participation. Confidentiality must be assured.
- The community needs to be made aware of the Guam AIDS Advisory Group and the collaborative private and government effort to create a centralized facility of care and Guam HIV Community Planning Group (CPG) to activate community support.
- The AIDS Education and Training Center (AETC) could be utilized to facilitate the training of caregivers and volunteers to deliver services to clients. Training could be integrated within the colleges and high schools.
- Social service programs should be formed to address PLWHA childcare needs and support.



## I. Educational Issues and Information Needs of PLWHA & Caregivers

### Existing Resources

- DPHSS STD/HIV Program in Mangilao offers literature helpful to PLWHA as well as Title II incentives. They also developed the *Prutehi Hao* Web Site for HIV/AIDS information. The link is [www.prutehihao.org](http://www.prutehihao.org).
- DPHSS Medical Social Services is the next link to services after receiving an HIV diagnosis or when applying for services as a PLWHA for the first time.
- Private and public clinics provide specific HIV/AIDS information to PLWHA. Such information includes instructions on how to read lab results, diet and nutrition guidelines, medical adherence issues and opportunistic infection identification. +
- Red Cross provides caregivers with basic HIV/AIDS outreach and education.
- Internet access allows clients and caregivers to be more connected to services, products and interventions for PLWHA.
- Local libraries provide archived and current HIV/AIDS of interest to PLWHA.
- CVS ProCare provides personalized service to PLWHA and also works with MSS to assist clients with treatment issues.
- National HIV/AIDS Hotline is available for clients to access HIV/AIDS information.
- Local pharmacies offer HIV/AIDS information through free pamphlets and circulars.
- The GMH nutritionist is a valuable resource providing guidance to PLWHA.
- Alternative therapies that benefits PLWHA include non-invasive acupuncture, massage, local medicines and non-traditional healing)
- Social Security eligibility limitations sometimes service delivery to clients living with HIV/AIDS.
- DPHSS Maternal Child Health provides information on HIV/AIDS.
- The Office of Minority Health (OMH) can be tapped to access appropriate programs that can benefit PLWHA.
- University of Guam Community Resource Development office is a client-participant entity for focus groups, consortiums and specialized training.

### Challenges/Barriers

- Clients believe that there was not enough information about their condition after they were informed of their HIV status.
- Understanding side effects and education of HIV medications and articulating them to clients is very much needed. Competent and knowledgeable doctors specializing in HIV/AIDS are needed.
- Language barriers prevent appropriate health care services to be properly delivered. Cultural barriers may affect how services are delivered and to whom. For example, it may be difficult for a client to ask for help because of pride and shame instilled within his culture.
- Gender barriers may involve acceptable ways of treatment for PLWHA. For example, a spouse or parent may refuse treatment to be administered to their family member unless given by specifically a male or a female individual.
- Age barriers. It is legal to have a minor test for HIV but if the test comes back positive, the minor or counselor is not obligated to inform the parents of the results.

- Social barriers include the perceived stigma, shame and guilt of being HIV positive.
- Guam's small size and close-knit community can be a barrier to preserving confidentiality, even among caregivers. Some clients access help from off-island sources.
- Family barriers can result from the perceived embarrassment and shame a person might bring to the family because of their HIV status.
- Lack of insurance coverage can add to the stress of the client and family.
- Confidentiality training is needed for caregivers to preserve the integrity of the service delivery for the client.
- Eligibility requirements can exclude PLWHA from services due to high income, citizenship qualifiers, other pre-existing conditions and age.
- Insurance co-payments may be out-of-reach for clients.
- Insurance caps limit needed services to PLWHA such as counseling and physical therapy sessions.
- Social Security eligibility limitations can impact services available to PLWHA.
- People unwilling to understand the HIV/AIDS epidemic and continuing risk behaviors can cause the epidemic to become more widespread.
- Lack of information for updated clinical trials for new HIV/AIDS medications.
- Continuous training and information needed for caregivers to help PLWHA more effectively.
- Lack of community support for PLWHA.

### **Recommendations (I)**

- Include the AIDS Education Training Center (AETC) in the training of caregivers and service providers for PLWHA. Training must be updated regularly.
- Link up with Guam's Washington delegate in Congress to advocate for Guam's System of Care Services.
- Revamp eligibility requirements to be more inclusive of HIV/AIDS. This may require a restructuring of insurance coverage.
- Client advocates must form a political lobbying body to introduce federal health care funding for HIV/AIDS programs.
- Establish localized HIV/AIDS education campaigns with culturally competent, linguistically appropriate, and client-sensitive content.
- Formulate a plan to address all entitlement programs and eligibility requirements in one document or resource guide. Include input from PLWHA in every step of the planning processes for HIV/AIDS care.
- Training and workshops for HIV/AIDS case management can be facilitated by the AIDS Education and Training Center (AETC). Measurable competency in care should be mandatory (by exit surveys, client satisfaction surveys, service quality review boards, evaluation panels, and client polls).
- Feedback from clients could identify needs where caregivers and service providers could improve client care.

## **J. Psycho-social Need Issues (Mental Health)**

### **Existing Resources**

- Volunteers fill in gaps not covered by other service delivery entities.
- Private counselors from private clinics are used to address issues of PLWHA and process struggles living with HIV/AIDS.
- Medical Social Services (informal counseling services) is another counseling resource for clients.
- Inclusiveness of PLWHA in focus groups and consortia is needed at all times to ensure the voices of clients are heard and acted upon.
- Churches that are compassionate to HIV/AIDS issues are sources of support for clients.
- Families and friends that are supportive and non-judgmental are critical in the life of a PLWHA. Clients have reported this as an important component in their psychosocial support system.
- Internet chat and online services enable clients to be in touch and updated regarding HIV treatments and services for clients.
- Spirituality and prayer are empowering and healing elements for many PLWHA.
- The different churches on Guam have been identified as sources of strength and healing for some PLWHA. This includes interaction with clergy.
- Gay and lesbian community support for clients who self-identify as gay or lesbian is sometimes present.
- Employers who are accepting of a client's HIV status and who keep confidentiality intact are very important.
- Other PLWHA support each other through regular meetings, phone calls and email. This ensures a type of support system in the absence of a formalized support group meeting.
- "Hope For A Cure" is a local organization that advocates for the cure of HIV.

### **Challenges/Barriers**

- The stigma associated with HIV is often one of shame, guilt, promiscuity, drug use, and embarrassment.
- Lack of HIV/AIDS case managers prevent services from being delivered to clients and their families.
- Lack of HIV/AIDS case management programs means that a structured plan of care and support is not being delivered to clients.
- Lack of medical case management points to another important need for the System of Care Services to address.
- Lack of HIV/AIDS specialists prevents care to be delivered to PLWHA.
- Fear of HIV/AIDS disclosure by PLWHA about their HIV status may be a barrier to accessing care and services for some people.
- Fear of ridicule, misinformation, stigma and stereotyping from the community can hinder service delivery to PLWHA.
- Fear of misinformation about HIV/AIDS and possible rejection from others is another barrier to HIV/AIDS care.
- Lack of free childcare services can prevent parents from accessing health care at any level.
- Lack of faith in Guam's ability to deliver accessible quality health care for all people discourages many clients.



- Lack of estate planning for survivors and families can add stress to the client and family.
- Lack of free legal services for PLWHA who cannot afford it is needed to resolve client legal issues.
- Confidentiality is compromised and not ensured. When client confidentiality is breached, no one appears to be held accountable with appropriate consequences on Guam.
- The socioeconomic climate and attitude on Guam is not conducive at this point for progressive support and change.
- PLWHA often have reduced personal resources and cannot afford computers and Internet services.
- There appears to be fewer places on Guam where PLWHA can access free or low-cost supportive counseling services that do not require insurance coverage.
- Prevention case management program services do not exist on Guam for PLWHA. This program is needed to help reduce future HIV infections, to assist clients in making responsible personal decisions regarding HIV/AIDS, contain the spread of the HIV virus and to make Health Education and Risk Reduction (HE/RR) interventions realistic and effective.

### **Recommendations (J)**

- Community-based organizations need to provide psychosocial support for PLWHA. Free or low-cost counseling services that do not require insurance coverage are needed for PLWHA. Public awareness community events for HIV/AIDS education must take place.
- Support groups must be consistent and facilitated by professionals and stakeholders alike. A community forum is needed to provide doctors and caregivers feedback on community needs for PLWHA.
- Funding streams must be identified to support peripheral issues such as childcare, estate planning, survivor benefits, and so forth. These are important to clients and a system of addressing these needs must be developed as part of the System of Care Services.
- A central facility dedicated for the benefit of PLWHA, their families and caregivers is needed. Clients can use the center to access materials to deal with their HIV status, have access to on-line computers, have a safe-haven for respite purposes, and for empowerment and ownership to address issues of HIV/AIDS.
- An HIV prevention case management program must be funded and developed to help PLWHA reduce HIV infection through containment and HE/RR interventions.

### **K. Financing Medical Costs**

#### **Existing Resources**

- Insurance companies that cover and pay for HIV/AIDS care can pay for doctor and service provider costs.
- DPHSS Medically Indigent Program (MIP) has helped clients finance their health care costs.
- Self-payers personally foot their own way through expenses.
- Off-island pharmacy support from ProCare sometimes offsets health care costs for some clients.
- Supportive doctors who understand the need to fund medical costs and expenses are aware that their services have value and that they must be compensated for the work they do.

### Challenges/Barriers

- Inability of Government of Guam to pay for MIP program reduces health care access.
- Inadequate hospital facilities for specialized care leave many clients without the care they need.
- Having to go off-island for care is extremely expensive and not always an option for these clients.
- Multiple-diagnosed client needs (HIV, ADHD, TB, Diabetes, etc.) are not addressed.
- Clients' lack of understanding about health care coverage often leaves them without the care that is available to them.
- Insurance companies that do not cover HIV/AIDS care leave gaps in possible health care coverage options.
- Outer-islanders coming to Guam for HIV/AIDS care have taxed an overburdened health care system on Guam.
- Increasing need to assist PLWHA with health care coverage.
- Rising number of new HIV infections and fewer resources mean that fewer and fewer people will get the care they need.
- Skyrocketing medical costs for HIV medications will make it prohibitively expensive to attain for many PLWHA.
- Policy makers who do not fully understand HIV/AIDS health care costs or the needs of PLWHA cannot properly forecast how much to budget, appropriate and allocate.

### Recommendations (K)

- Representatives from the Department of Revenue and Tax, which regulates Guam's health insurance industry, and MIP at DPHSS must be included on any AIDS advisory consortia, or Governor's Inter-agency AIDS Task Force.
- Local AIDS non-government organizations (NGOs) should work with the Guam Medical Society, DPHSS, the Governor, the Department of Revenue and Tax, and legislators, to advocate for insurance laws that mandate medical, vision, dental, and behavioral coverage be provided in all insurance plans offered on Guam.
- Local AIDS NGOs should obtain national technical assistance to conduct training for island leaders on current standards of drug coverage by insurance plans, and how Guam should update defined formularies provided in island insurance plans to assure coverage of newly emerging medications.
- Have HIV/AIDS specific case management funding identified by local government. This can be justified by data collection found in Guam CPG Plan.
- Establish localized HIV/AIDS prevention case management education campaigns for at-risk PLWHA with culturally appropriate, linguistically proper and outcome-based interventions. This is needed to contain the HIV/AIDS epidemic and to reduce the possibility of re-infections that could accelerate the deterioration of health of PLWHA.
- Clients from outer islands must show self-sufficiency or residency before they can qualify for services, or an agreement with their government to defray some of the health care costs is needed. Clients must be given support to be more self-sufficient and empowering to deal with their psychosocial needs.
- Policy makers must be more aggressive in ensuring that Guam receives all money it is entitled to have and then uses it accordingly. Policy makers and client advocates must form a political body to lobby for sustainable federal health care funding for HIV/AIDS programs.





APPENDIX A  
Outcome Report of  
**the First Guam HIV/AIDS Consortia Conference**  
Held April 26, 2002  
Onward Agana Beach Hotel, Tamuning, Guam

### **Introduction**

The Guam HIV/AIDS Consortia Conference was a collaborative effort between public agencies and community non-profit organizations supported by two grant funding sources<sup>1</sup>, with in-kind resource help from a larger network of programs and volunteers. This outcome report has been distributed to you and all network contacts who responded to the invitation saying they were interested to be involved in this and future event efforts. Some of you were able to attend, and some had prior commitments, and some planned to attend but had to respond to the “measles outbreak crisis” that was declared on the same day.

One of our main objectives for this “First” conference was achieved, which was to begin organizing communications and links within Guam’s network(s) of service providers, care-givers, and consumer clients who address the needs of *Persons Living With HIV/AIDS (PLWHA)*. But we have only achieved the “to begin” part. The longer range goal is developing and continuing to improve what can be called a “system of care” on Guam for PLWHA.

**Help us** with the action needed for that longer range goal; **share this report** document (photo-copy it as you wish, refer to it in your program documents and materials). Not only will this help inform a wider range of people in Guam’s on-island network, but our regional and national network linkages can also become more aware, sensitive, and supportive of this initiative.

Included with this report (see last page or if *Prutehi Hao* web site icon click) is a **Membership Application Form** if you are interested in being associated with and kept informed by our Guam Ryan White CARE Act Needs Assessment Advisory Council. We intended to use electronic and communication media for most exchanges collecting your input, advice and getting your assistance (face-to-face meeting time will be efficient and minimal). If you attended the Consortia Conference and just haven’t submitted your form, yet, **THIS IS A REMINDER!!**

### **PEOPLE PARTICIPATION**

Through communications among persons known by the planning group organizers, **we produced a contact list of 89 persons who confirmed they were interested and willing to participate in Ryan White Planning for PLWHA during the coming year** as service providers or PLWHA or family/caregivers of PLWHA or community volunteers. One-fourth (22 persons) confirmed their interest but were unable to attend due to prior commitments. We had an attendance by 56 persons (84% of those who *RSVP’d* they would try to attend), with 11 persons (16%) called off to address the declared measles outbreak (from Naval Hospital and Guam Public Health).

### **Network Involvement**

**We have produced an initial, *Draft Network Directory Listing with the contact information*** for these 89 persons divided into four sections: (1) Service Providers: Government, (2) Service Providers: Private Health/Social/Medical Services, (3) Service Providers: Community Non-Profit

<sup>1</sup> Funded in part by a Mini-Planning Grant from the Association of Asian Pacific Community Health Organizations (AAPCHO) to Guam DPHSS, and by sub-contract of Ryan White Title III funding from HRSA, US Department of Health and Human Services via Guam DPHSS to the University of Guam.

Organizations (501C3's), and (4) Community Volunteers and Advocates. The chart table below provides detail of organizations linked in this network. We hope this will evolve into a "resource" for increasing and improving the quality of communications.

<b>Draft Network Directory Listing</b>		
<b>Service Providers: Government Programs</b>		<i>(number of persons = 56)</i>
Public Health & Social Services	Guam Memorial Hospital	U.S. Naval Hospital
Dept. of Youth Affairs	Guam Housing & Urban Renewal	University of Guam
Mental Health & Substance Abuse	Dept. of Corrections	Guam Community College
<b>Service Providers: Private Health/Social/Medical Services</b>		<i>(number of persons = 14)</i>
Pacific Human Resource Services	Bio-Path Labs	Ia' Amti Medical Clinic
Home Health Care	Pacific Behavioral Health Clinic	Seventh Day Adventist Clinic
Marianas Physicians Group	Pacific Area Counseling Network	
<b>Service Providers: Community Non-Profit Organizations (501c3's)</b>		<i>(number of persons = 11)</i>
Guam Legal Services, Inc.	Coral Life Foundation	Guma Mami, Inc.
Salvation Army (Light House Recovery)		
<b>Community Volunteers and Advocates</b>		<i>(number of persons = 8)</i>

This is only a beginning and we are sure you can already see public or private or NGO services that are not listed here who (a) are on-island, (b) work with you, and (c) are willing to join if someone (like you) just asked.

### **Needs Assessment Issue Identification**

Conference participants produced a *Listing of Issues and Question Themes* to be addressed by the Needs Assessment studies which the Ryan White Planning Project will be conducting in the coming months.

An *Affinity Diagram Process* was employed to "brainstorm" specific issues and concerns from consortia conference participants, and to then refine and cluster these into meaningful theme or subject matter areas. Through out the morning presentations by representatives from consumer clientele and various service provider areas, issues were written by two "recorders" who also solicited issue ideas from the audience after each speaker session. These were typed up and copies distributed to all participants after the lunch break. In the afternoon participants were divided into three small working groups (to encourage optimum contribution from each person). All participants were provided post-it note pads, and asked to review the brainstormed "rough" listing produced in the morning in order to write refined/improved issue or concern statements (one refined statement on each post-it note) Each participant wrote 4-5 of what they felt were the most critical issue topics and concerns that must be addressed for the development of what we can call a "system of care" for PLWHA on Guam. In their separate groups, participants placed their post-it note statements onto an easel board and proceeded to cluster and re-group all their issue/concern statements in to common theme areas. When they reached a

consensus on an agreeable set of cluster groupings, participants then developed a label or phrase for describing the common theme of that cluster.

These labeled clusters by the three working groups have been matched up and combined where there was similar issue themes identified by two or all three of the groups. This refinement process led to the identification of seven (7) Issue Themes from the specific input by the consortia conference participants.

**Issue Themes to be Addressed by Guam's Ryan White CARE Act  
Needs Assessment and Planning Project 2002-2003**

- 1 Island Resource Collaboration, Grant Writing, and Planning for Local/Regional Needs
2. Needs Assessment and Data Surveillance
- 3 Legislative Policy Advocacy and Lobbying
- 4 Service Needs: Support, Mental Health, Housing, and Case Management
5. Financial Needs: Insurance and Programs for Medical Expense Coverage
6. Medical Care Needs: Access and Treatment/Therapies Support
7. Education/Training Needs of Medical Health Professionals and the Community

The expanded table chart below presents these issue themes with the labeled clusters used to define them, and the specific refined statements listed by participants (A, B, C,..... M, N...).

1. Island Resource Collaboration, Grant Writing, and Planning for Local/Regional Needs
<p><i>Governance / planning-</i> Group 2</p> <ul style="list-style-type: none"> <li>A. Development of System of HIV/AIDS Care Council</li> <li>B. Form a network among agency grant programs.</li> <li>C. Funding &amp; resource coordination to avoid duplication of services while providing comprehensive services</li> <li>D. To help out or give people the sources to help</li> <li>E. Dedication of grant writing group for HIV/AIDS</li> <li>F. How can we secure additional resources I e. funding.</li> </ul>
<p><i>Funding Sources-</i> Group 1</p> <ul style="list-style-type: none"> <li>A. Grants * AIDS Education &amp; Training Center * Nutrition Services</li> <li>B. Sources, Funding</li> <li>C. Resources (Funds).</li> <li>D. How can we secure funds for Case Management?</li> <li>E. Location of additional fund grants for care support for PLWHA.</li> <li>F. Seek more Federal Funds. <span style="float: right;"><i>(continued next page)</i></span></li> </ul>
<p><i>Policy-</i> Group 1</p> <ul style="list-style-type: none"> <li>A. More consortia meetings and networking for HIV/AIDS educator's workers/providers/ community educators establish Guam foundation and build on it.</li> <li>B. Need for IDU needled exchange programs</li> <li>C. Outreach to Intravenous drug users (IDUs)</li> <li>D. Employment opportunities (jobs).</li> <li>E. Flexible Part time or flex time Employment</li> </ul>



**Policy- Group 1 (cont'd)**

- F. Given Guam's low number of youth HIV+, how can we better serve this population?
- G. How can HIV positive people receive their medicine without having to stop verifying income eligibility: Given the need for income
- H. Guaranteed income support –Patient disability stats
- I. How can we use the Guam Legislature to our advantage in passing laws that better support PLWHA (Disability)?
- J. Clarification and amendments for Medicaid/ MIP requirements to allow easier qualification for PLWHA

**Regional Issues-Group 2**

- A. Inclusion of Micronesian & other ethnic groups in councils, meetings surveys, etc.
- B. New networking options in the regional level.

**2. Needs Assessment and Data Surveillance**

**Surveillance / Accurate Counts- Group 1**

- A. Obtaining recent & accurate statistics (# of persons infected).
- B. How can a more reliable count of PLWHAs be completed ?
- C. Estimate HIV/AIDS cases in Guam and then make HRSA understand Guam's unique condition  
Have HRSA change criteria to accommodate Guam's unique environment (also all the other PI environment)
- D. What kind of prevention care management services are available?

**Data/Surveillance- Group 2**

- A. A survey/ Census must be conducted to try to determine Guam's population with HIV/AIDS
- B. Assess the total# of PLWHA accessing HIV health care services of Guam
- C. Conduct survey of clients to identify their individual needs, including:  
1 Medical, 2. Financial , 3. Housing, 4. Support System , 5. Psycho- social
- D. What is the actual number of HIV positive clients accessing medical/ psycho-social services?
- E. Study spirituality needs that are important in support
- F. What kinds of psycho-social support services can be developed for PLWH & their families?

**3. Legislative Policy Advocacy and Lobbying**

**Lobbying- (Local/On-island and Regional/National) Group 2**

- A. What can be done to motivate HIV & individuals to be proactive & vocal about HIV policies & issues that affect them?
- B. Who can lobby the legislature to add HIV/AIDS to the MIP disability list.
- C. Educate Political leaders that HIV services matter.
- D. Lobby lawmakers for funding.
- E. Who can lobby the Federal gov't (CDC) to modify the current process allotting HIV funding?

***Financial Funding / Care Condition- Group 2 (cont'd)***

- D. Public Health should take care of free medication like other countries that do
- E. If there's no other alternative for meds. Where do we go?
- F. Help people where to get the assistance private or public sections.
- G. Are PLWHA's who work a full-time job able to receive disability?
- H. Investigate & revise of program service qualifications and eligibility criteria
- I. Establish Guam's eligibility criteria

***Financial Needs Group 3***

- A. Can we research the qualifications required to receive Public assistance
- B. Financial assistance
- C. Identify common resources that will help HIV clients

**6. Medical Care Needs: Access and Treatment/Therapies Support**

***Treatment Access- Group 1***

- A. Transportation
- B. Transportation
- C. Availability of Transportation Services & Housing Facilities.
- D. Medication's
- E. Medicine / Health Insurance \* Eligibility for programs \* Lobby for greater coverage
- F. Maintain continuing of availability of meds & medical insurance coverage.
- G. Can Guam ever qualify for SSI?
- H. Health insurance
- I. Stable Conditions Access to needed meds.
- J. Employment opportunities compatible with medical conditions.
- K. Clinics
- L. Medications
- M. Medications
- N. Assurance for uninterrupted medication TA for PLWHA
- O. How can we avoid breaks in the content of care regarding medication?

***Medication Needs – Group 3***

- A. Regarding the medication/ therapies these tend to be difficult to follow
- B. What medical care services can (Guam) offer once someone tests positive for HIV? Esp. those without medical insurance
- C. We need to find a way to keep up with the latest medications (being) created and (find ways) to make them available on Guam.
- D. Pharmacies
- E. Medication resources
- F. How can funds for medication needs be increased? Where can we obtain these additional funds?

## 7. Education/Training Needs of Medical Health Professionals and the Community

### *Medical/Health Provider Needs – Group 3*

- A. We need to find more Dr's that are more knowledgeable on HIV/AIDS
- B. Need to train MDs on proper care of PLWHIV
- C. Private doctor to provide medical care for HIV/AIDS clients
- D. To establish a memo of understanding between providers (both private/ private) to report cases of HIV/AIDS
- E. Need more physician collaboration to take care of PLWHIV

### *Education and Training-Group 1*

- A. Establish AETC in Guam.
- B. Have general information
- C. Training center for MD's clinics, organizations for assisting PLWHA
- D. Education
- E. Health Provider Preparedness \* Standards of care \* continuing education \* list of sources of new meds.
- F. AIDS Education
- G. Education Community & Physicians.
- H. Service Directory.
- I. Educate community health care centers and providers- on stats, services available, networking.
- J. Outreach Services to be more knowledgeable of women-at-risk.
- A. Motivate other practitioners to care for patients.

### *Training and service needs Group 2*

- A. Explore needs for, and ways to provide, HIV/AIDS clinical training & updates to medical providers on a consistent basis
- B. Program staff & administrators need training to understand confidentiality and develop inter program MOU's
- C. A truly anonymous non-threatening testing site and services must be established to conduct the testing. Advertise to seek volunteer workers to reach out to clients like shelters general population must be educated and convinced that every sexually active individual must be tested
- D. Advertise to seek volunteer workers to reach out to clients like shelters.
- E. Seek Health care givers for support (continued next page)
- F. The general population must be educated and convinced that every sexually active individual must be tested.
- G. Need for out reach and educating people on prevention.

### *Education- Needs Group 3*

What can be done to educate the island population about HIV/AIDS in order to remove stigma & promote awareness, acceptance for HIV+ individuals.



## APPENDIX B

### Guam HIV/AIDS Title III Advisory Council: Needs Assessment SERVICE PROVIDER SURVEY 1

The information collected here is vital for assessing existing services and estimating HIV/AIDS client case loads **PLEASE FILL IT OUT EVEN IF YOU DO NOT HAVE SUCH CLIENTS AT THE PRESENT TIME.**

This survey was designed to identify medical care service providers who have HIV/AIDS patients. There are no risks to your agency program, and responses will not violate client confidentiality. If you are not the best person to answer these questions, feel free to pass it along to someone who may have more knowledge of the service program.

**This survey of services will be supported by another survey directly targeted at Persons Living With HIV/AIDS (PLWHA).** The combination of studies will help Guam's Advisory Council understand met and unmet needs for HIV-related services. If we have not contacted you regarding this second study, yet, but you do have HIV/AIDS clients, we encourage you to contact us because we need your help!

**We are asking you to confirm and provide program identifier information.** We assure you that data analyses and study findings will not specify programs by name. Results will refer to general categories (e.g., the public agency sector, or health care industry, or among medical doctors, and so on). The University of Guam is not affiliated with any service provider, and all findings will be public information.

1 Name: \_\_\_\_\_ Practice/Agency Affiliation: \_\_\_\_\_  
1b (Phone): \_\_\_\_\_ (Email): \_\_\_\_\_

2a. Nature of agency/program service:

☐ Public agency program ☐ Medical/Health Care business ☐ Non government or non-profit ☐ Military program

2b. Which best describes your organization? (one response only)

☐ HIV/AIDS service organization/ program ☐ Multi-service agency that includes HIV/AIDS services  
☐ Medical/ Health clinic ☐ Multi-service agency with no specific HIV/AIDS program  
☐ Community based organization (not AIDS-specific) ☐ Substance abuse treatment facility  
☐ Hospital (Only) ☐ Other (specify): \_\_\_\_\_

2c. Does your organization/practice target particular populations? (Check all that apply)

☐ Race/ethnicity? (e.g. Gay Men of Color Grant Program) ☐ Age Group? (Specify, e.g. elderly, pediatric)  
☐ Gender? (e.g. Women's Health Clinic) ☐ Special Needs? (e.g. injection drug users, homeless individuals, mental illness)  
☐ No particular population targeted

3 Which of the following does your agency program most often provide?

(Your most developed services – check no more than three.)

☐ Medical care ☐ Dental care ☐ Counseling/mental health  
☐ Complementary/alternative therapy ☐ Substance abuse treatment ☐ Dietary education / nutrition  
☐ Access (e.g., child care, transportation) ☐ Housing ☐ Benefits/financial assistance  
☐ Family services (e.g., respite care, legal assistance) ☐ Other (specify): \_\_\_\_\_

4. Official reported cases of HIV/AIDS for Guam are restricted only to those who test positive on island. We have no estimate of HIV/AIDS cases on Guam who tested elsewhere, and who may not be receiving any public agency HIV/AIDS program services

**Please provide your best guess on the following and we will sort out duplications.**

Category	Estimate Total Number
a. All Patients/Clients you serve	
b. HIV positive not AIDS	
c. Diagnosed with AIDS	

5. If you have clients living with HIV or AIDS, please estimate the number of those tested on Guam or off island:

**Tested on Guam:** \_\_\_\_\_

**Tested off-island:** \_\_\_\_\_

Thank you! **RETURN TO the Ryan White Needs Assessment Study Office, by FAX to 734-1244 or call UOG 735-2050** to request a research assistant to pick-up your completed survey

## APPENDIX C

### Cover Page

#### Pacific Islands 2002 Survey for people living with HIV / AIDS or Affected by it.

Help us help you! Tell us what you need!

We need to hear from you, especially if you're someone who "never fills out surveys." Your survey will be used to find out which care and treatment services are most important to People Living With HIV/AIDS (PLWHA) on Guam.

**This survey is completely anonymous and voluntary.**

Don't tell us your name. Just tell us what you need. This survey can take up to an hour, so if you want, we have gift certificate "thank-you" for your time.

You may receive other copies of this survey from more than one service provider or agency. Please fill out and return this survey only one time.

Need help?

We encourage you to accept the help of a trained interviewer. They can help you to read, understand and complete this survey more quickly, please call the Coral Life Foundation at 727-2435, or the UOG: Ryan White Title III Project at 735-2050. Personal, confidential help is available, and they will meet you at your convenience and site choice.

Deadline: Please return before December 01, 2002

### Page 2

Instructions for completing the 2002 Survey for people living with HIV / AIDS

- You don't need to answer any questions that you don't know how to answer.
- Leave blank any questions you don't want to answer or any that make you feel uncomfortable.
- Your HIV/AIDS care or access to services will not be affected if you decide not to answer any or all of the questions.
- Tear off the last page to keep for your own reference.
- For a child with HIV/AIDS, his/her parent, guardian or caregiver may fill out this survey while representing, as *much as possible*, the child's point of view.
- For an individual who is physically and emotionally ill, a friend, family member or caregiver may fill it out while representing, as *much as possible*, that individual's point of view.
- Return the survey to the person or agency that gave it you, or use the postage-paid envelope and drop it in any mailbox. Return by December 01, 2002.

Remember!

You may receive other copies of this survey from more than one person or agency.

Please complete and return this survey only one time.

1. I am filling this out for \_\_\_\_\_ myself \_\_\_\_\_ A person who has  
☐ check if assisted by an interviewer. HIV/AIDS

If filling out for another person, please indicate your relationship to that person:

Relationship: \_\_\_\_\_

NOTE: For those who are filling this survey out for someone else, from this point forward the questions will be phrased as if to the PLWHA-, please accommodate.

2. a. What year were you (the PLWHA) diagnosed with HIV? \_\_\_\_\_  
 b. on Guam  
 off-island
3. a. Have you also been diagnosed with AIDS?  
 \_\_\_\_\_ No \_\_\_\_\_ Yes (indicate year of diagnosis) \_\_\_\_\_  
 b. and city/ state where tested: \_\_\_\_\_
4. What is your first language? \_\_\_\_\_
5. Gender: \_\_\_\_\_ Male \_\_\_\_\_ Female \_\_\_\_\_ Transgender
6. What was your age at last birthday: \_\_\_\_\_
7. Primary Race/Ethnic Background:  
 (Please check one category that best describes you.)

Pacific Islander _____ Chamorro _____ Chuukese _____ Kosrean _____ Yapese _____ Pohnpean _____ Marshallese _____ Palauan _____ Other Pacific Islander	Asian _____ Filipino _____ Other Asian (Japanese, Chinese, etc.)
	Other racial/ethnic groups _____ African-American _____ Hispanic _____ Caucasian _____ Other (specify) _____

8. How do you think you became HIV-positive?  
 \_\_\_\_\_ Man to woman \_\_\_\_\_ Using or sharing contaminated needles  
 \_\_\_\_\_ Man to man \_\_\_\_\_ Contaminated blood products  
 \_\_\_\_\_ Woman to woman \_\_\_\_\_ Other, please specify: \_\_\_\_\_  
 \_\_\_\_\_ Mother to baby \_\_\_\_\_  
 \_\_\_\_\_ Not sure \_\_\_\_\_



9. If you do not reside on Guam, but access service on Guam, which island are you from?

☐ I reside on Guam  
☐ Saipan, ☐ Rota, ☐ Tinian  
☐ Yap, ☐ Chuuk, ☐ Pohnpei, ☐ Kosrae  
☐ Marshall Islands ☐ Palau ☐ Other (specify) \_

10. Do you receive primary medical care for HIV/AIDS? ☐ Yes ☐ No  
(If YES, Check all locations where you receive care)

☐ Public Health Northern (Dededo)  
☐ Public Health Central (Mangilao)  
☐ Public Health Southern (Inarajan)  
☐ Private Doctor on Guam  
☐ Naval Hospital  
☐ Off-island Medical Care (specify city/country) \_\_\_\_\_  
☐ Alternative (non-western medicine)

11. Have you been referred to a specialist for management or care of an HIV/AIDS related condition/ and have you experienced difficulty getting service on Guam?

☐ No  
☐ Yes, and the difficulty was (check all that apply):  
☐ No specialists/service available on-island.  
☐ Service available, but insurance not accepted  
☐ Other difficulty (specify): \_\_\_\_\_

12. If you receive HIV/AIDS medications or treatments, how are they paid for?

<input type="checkbox"/> Medicare/Medicaid	<input type="checkbox"/> Medical Indigent Program
<input type="checkbox"/> Private Insurance or HMO	<input type="checkbox"/> V.A. Medical Assistance
<input type="checkbox"/> My self, family/ partners	<input type="checkbox"/> Maternal Child Health
<input type="checkbox"/> AIDS Drug Assistance Program (ADAP)	<input type="checkbox"/> Other (specify) _____

13. How are your medical bills being paid?

<input type="checkbox"/> Private health insurance	<input type="checkbox"/> COBRA health insurance extension
<input type="checkbox"/> Medicare	<input type="checkbox"/> Medicaid
<input type="checkbox"/> Ryan White CARE Act funds	
<input type="checkbox"/> Out of own pocket by you or your family	
<input type="checkbox"/> AIDS Service Organization emergency funds	
<input type="checkbox"/> Health Quest	<input type="checkbox"/> Quest Net
<input type="checkbox"/> VA or other military	<input type="checkbox"/> HDAP, HSPAMM
<input type="checkbox"/> MIP (Medical Indigent Program)	<input type="checkbox"/> Don't Know
<input type="checkbox"/> Other (specify) _____	

14. Have you used any of the following service providers to improve your quality of life due to your HIV/AIDS condition? (If YES, Check all that apply.)
- ☐ Guam Housing Urban Renewal Authority  
☐ Guam Department of Public Health and Social Services  
☐ Guam Department of Mental Health and Substance Abuse  
☐ Guam Memorial Hospital  
☐ Guam Coral Life Foundation  
☐ CNMI Department of Public Health and Social Services  
☐ CNMI Department of Mental Health and Substance Abuse  
☐ CNMI Hospitals (specify) \_\_\_\_\_  
☐ Other island or state services (specify) \_\_\_\_\_  
☐ None of the above
15. Have you experienced difficulty in communicating with these service providers?
- ☐ Yes                      ☐ Sometimes                      ☐ No
16. Which of the following persons do you feel comfortable about revealing your HIV status?
- ☐ Health care specialists                      ☐ Family  
☐ Priests/Ministers/spiritual advisors                      ☐ Village neighbors  
☐ Friends                      ☐ Co-workers
17. What best describes your current work situation?
- ☐ Employed full-time                      ☐ Unemployed – homemaker  
☐ Employed part-time                      ☐ Unemployed – looking for work  
☐ Working part-time and on disability                      ☐ Unemployed – not looking for  
☐ Not working – on full disability                      work at this time  
☐ Not working – applied for disability                      ☐ Retired ( and whatever?)  
☐ Not working – student                      ☐ Other (specify) \_\_\_\_\_
18. Do you receive any of the following benefits? (Check all that apply)
- ☐ Food stamps                      ☐ Long term disability  
☐ Rent supplement                      ☐ Short term disability  
☐ Social Security Disability Income (SSA/SSDI) – permanent disability  
☐ Temporary Assistance to Needy Families (TANF). Formerly AFDC  
☐ Veterans assistance                      ☐ Workers compensation  
☐ Insurance payments                      ☐ Retirement  
☐ HIV/AIDS drugs (ADAP)                      ☐ Other public assistance (specify) \_\_\_\_\_
19. Have you ever been homeless (no residence to stay for the night?)
- ☐ No                      ☐ Yes
20. What is the longest amount of time you were homeless in the last three years?
- ☐ I have not been homeless in the last three years  
☐ 1 - 7 days                      ☐ A week to a month  
☐ More than a month to a year                      ☐ More than a year

21. What is your current living arrangement? (Check only one.)
- ☐ Own house, apartment, condo, or mobile home  
☐ Rent house, apartment, condo, or mobile home  
☐ Rent a room or space in a house  
☐ Stay for free or crashing with friends or relatives  
☐ HIV/AIDS housing facility or housing  
☐ In a drug or alcohol treatment center  
☐ In a half-way house/transitional housing  
☐ In a hotel or motel  
☐ Hospital or skilled nursing facility  
☐ In a shelter      ☐ Jail or correctional facility      ☐ Other (specify) \_\_\_\_  
☐ Homeless – on the street, beach, in a car, abandoned building, other: \_\_\_\_\_
22. Do you live with other persons?
- ☐ I live in a facility, institution or group setting  
☐ I live alone in a house or apartment  
☐ I live with others (check all that apply):  
     ☐ Partner/wife/husband      ☐ Adult family member or relative  
     ☐ Adult friend/roommate      ☐ Children (How many?) \_\_\_\_\_  
     ☐ Others (specify) \_\_\_\_\_  
     How many people live with you? \_\_\_\_\_
23. Given your current house or residence setting, do you think emergency medical services (ambulance) could locate you in the event of an emergency?
- ☐ No      ☐ Not sure      ☐ Yes
24. Does the government or another organization help pay for your housing?
- ☐ No  
☐ Not sure  
☐ Yes – Please check all the answers that are true about you  
     ☐ I have a Section 8 certificate or voucher  
     ☐ I live in subsidized or public housing  
     ☐ I get assistance for my housing, but don't know what it is called
25. Please answer the following questions to help us understand your financial situation. (Many project grants require us to specify levels of financial hardship)

A. What is your monthly gross income? (best estimate)	\$ _____ .00
B. Every month, how much do you pay in	\$ _____ .00
Rent/mortgage	\$ _____ .00
Gas, electric, water and phone	\$ _____ .00
Health care	\$ _____ .00
Medications	\$ _____ .00



27. If you had to move next month, indicate your preference for each pair of the following choices:

____ Have a place of your own even if it means paying more rent	<b>OR</b>	____ Share a place with other people
____ Move in with family or friends	<b>OR</b>	____ Move into shared housing with other PLWHAs in a building designed for PLWHA
____ Live in an apartment building where only people with HIV/AIDS live	<b>OR</b>	____ Live in an apartment where people live regardless of HIV/AIDS status
____ Live in a building where services are available on a daily basis	<b>OR</b>	____ Services can be located external or separate of residence
____ Move to another village if you can pay less for rent	<b>OR</b>	____ Stay in the village area where you live now

28. Do you feel that you been discriminated against when trying to get housing?

No, I have not been discriminated against when trying to get housing.

Yes-Please check all the reasons you had trouble getting housing

My race or ethnic background

My religion

My sexuality: gay, lesbian, bisexual, or transgender

The number of children in my family

My health: HIV infection or AIDS

My disability \_\_\_\_\_ Other: \_\_\_\_\_

29. Have you experienced other difficulty getting housing?

No, I have not had trouble getting housing.

Yes, Please check all of the reasons you had trouble getting housing.

My alcohol or drug use

## My mental illness

My immigration status

My bad credit

I couldn't afford the monthly rent

I didn't have money for security deposit, first & last months' rent

I did not have transportation to search for housing

I had trouble getting housing for a different reason.

Explain:

30. For each service, indicate: (A) How important it is for you, (B) If it is available for you, (C) if you have accessed it; (D) How easy it was to access, and (E) Changes in your need.

Type of Service	A. Circle the Importance			B. Circle: Is it available?			C. Have you accessed it?		D. How eas was the Access?		E If this service w as available in Guam, would you access it?		
	H=	M=	L=	Y=	N=	DK=	Y=	N=	Y=	N=	Y=	N=	DK=
	High	Med	Low	Yes	No	don't know	Yes	No	Yes	No	Yes	No	don't know
<b>Medical Services:</b>													
Appointments													
Lab work													
Dental													
Alternative/Trad.													
Financial Support													
<hr/>													
<b>Case Management:</b>													
Treatment Advocacy													
Info & Referral													
Service Coordination													
<hr/>													
<b>Support Services:</b>													
Nutrition													
Printed Info													
Hotline													
Resource Guide													
<hr/>													
<b>Housing:</b>													
Transitional													
Long-term													
Rental Assitance													
<hr/>													
<b>Financial Assistance:</b>													
Medical													
Treatment													
Housing													
Transportation													
Fiscal Management													
<hr/>													
<b>Mental Health:</b>													
Substance Use													
Individual													
Couples													
Family													
Support Group													

NOTE: This question section format has been modified from the actual questionnaire version for inclusion in this report

30. For each service, indicate: (A) How important it is for you, (B) If it is available for you, (C) if you have accessed it; (D) How easy it was to access, and (E) Changes in your need.

Type of Service	A.			B.			C.		D.		E		
	Circle the Imporance			Circle: Is it available?			Have you accessed it?		How eas was the Access?		If this service was available in Guam, would you access it?		
	H=	M=	L=	Y=	N=	DK=	Y=	N=	Y=	N=	Y=	N=	DK=
	High	Med	Low	Yes	No	don't know	Yes	No	Yes	No	Yes	No	don't know

**Medical Care:**

Primary (early stage)

Intermediate

Advanced (late stage)

**Late Stage:**

Hospice

Burial

Skilled Nursing

**Other Services:**

Employment

Childcare

Legal

Emotional/Practical

*NOTE: This question section format has been modified from the actual questionnaire version for inclusion in this report.*



30. For each service, indicate: (A) How important it is for you, (B) If it is available for you, (C) if you have accessed it; (D) How easy it was to access, and (E) Changes in your need.

Type of Service	A. Circle the Importance			B. Circle: Is it available?			C. Have you accessed it?		D. How eas was the Access?		E If this service was available in Guam, would you access it?		
	H=	M=	L=	Y=	N=	DK=	Y=	N=	Y=	N=	Y=	N=	DK=
	High	Med	Low	Yes	No	don't know	Yes	No	Yes	No	Yes	No	don't know

**Medical Services:**

Appointments

Lab work

Dental

Alternative/Trad.

Financial Support

**Case Management:**

Treatment Advocacy

Info & Referral

Service Coordination

**Support Services:**

Nutrition

Printed Info

Hotline

Resource Guide

**Housing:**

Transitional

Long-term

Rental Assitance

**Financial Assistance:**

Medical

Treatment

Housing

Transportation

Fiscal Management

**Mental Health:**

Substance Use

Individual

Couples

Family

Support Group

*NOTE: This question section format has been modified from the actual questionnaire version for inclusion in this report.*

30. For each service, indicate: (A) How important it is for you, (B) If it is available for you, (C) if you have accessed it; (D) How easy it was to access, and (E) Changes in your need.

Type of Service	A. Circle the Imporance			B. Circle: Is it available?			C. Have you accessed it?		D. How eas was the Access?		E If this service was available in Guam, would you access it?		
	H=	M=	L=	Y=	N=	DK=	Y=	N=	Y=	N=	Y=	N=	DK=
	High	Med	Low	Yes	No	don't know	Yes	No	Yes	No	Yes	No	don't know

**Medical Care:**

Primary (early stage)

Intermediate

Advanced (late stage)

**Late Stage:**

Hospice

Burial

Skilled Nursing

**Other Services:**

Employment

Childcare

Legal

Emotional/Practical

*NOTE: This question section format has been modified from the actual questionnaire version for inclusion in this report.*





## Notes

## PIJAAG MEETING

Thursday, October 30, 2003 – Saturday, November 01, 2003

### **Present:**

Josie O'Mallan, *DPH*, Guam  
Fara Utu, *DPH*, American Samoa  
Bal Aguon, *DPH*, Guam  
Bernie Schumann, *DPH*, Guam  
Louisa Helgenberger, *Dept of Health Services*, FSM National  
Mailyynn Konelios, *Ministry of Health*, RMI  
Eleanor Sos, *DPH*, FSM Chuuk  
Margarita Torres-Aldan, *DPH*, CNMI  
Mary Muna, *DPH*, CNMI  
Alexis Silverio, *GUAHAN Project*, Guam  
Jill McCready, *DPH consultant*, Palau  
Hana Nguirchelbad, *Ministry of Health*, Palau  
Naseri Aitaoto, *DPH*, American Samoa

Paul Groesbeck, *Life Foundation*, Hawai'i  
Peter Silva, *Life Foundation*, Hawai'i  
Don Kyles, *Life Foundation*, Hawai'i  
Rodney Powell, *Life Foundation*, Hawai'i  
Laura Taimasa, *Life Foundation*, Hawai'i

Lina Sheth, *API Wellness Center*, San Francisco, CA  
Prescott Chow, *APIA Health Forum*, San Francisco, CA  
Javid Syed, *API Wellness Center*, San Francisco, CA  
ManChui Leung, *APIA Health Forum*, San Francisco, CA

Xuan-Lan Doan, *Hawaii Multicultural HIV Resource Project*, Hawai'i

Victoria Rayle, *CDC*, Atlanta, GA

Day 1: 7<sup>th</sup> floor conference room – 677 Ala Moana Blvd.

### PIJAAG Issues and Regional Laboratory Issues

#### Goals:

- § Review PIJAAG progress and overview
- § Share information and update on progress on Guam lab
- § Examine, discuss, and develop plan on how Guam can play a regional lab capacity role

TIME	CONTENT/ TOPIC	EXPECTATION
9:00 am	Welcome and Introductions	
9:30 am	PIJAAG Overview – Visioning Exercise	Discussion
10:30 am	Ongoing questions/issues	Discussion
11:00 am	Jurisdiction updates	Information sharing
12:00 pm	Lunch	
1:30 pm	Guam Laboratory Update	Information sharing
2:30 pm	Regional Lab Strategy	Discussion and Decision Making
4:00 pm	Standardization	Discussion and Decision Making – Create a Plan for Standardization
5:00 pm	Wrap up and Next Steps	
5:30 pm	Adjourn	

### REPORT BACK FROM VISIONING EXERCISE

#### AMERICAN SAMOA:

Current	ideal
outreach presentation media awareness campaigns CTR screenings meds home visits	more outreach surveillance/lab – want to do own tests law to mandate testing (health cards applicants, contract workers) program to order and distribute the meds

#### PALAU

Current	ideal
health education public information/social marketing CTR Pharmacy	prevention with positives media / social marketing psycho-social lab support and training



**FSM**

<b>Current</b>	<b>ideal</b>
centralized CTR limited outreach services lack of trained staff limited staff no medical access no case management inconvenient lab confirmation no referral services for nutrition, social service, mental health	improved CTR: more staff and trainings outreach: more NGO and community involvement increased health education early intervention  increase involvement of CPGs

**CNMI**

<b>Current</b>	<b>ideal</b>
facility only on Saipan but have linkage with other 2 islands clinical hours: only twice a week 3 staff only doing ELI test – Orasure stopped because of transportation issues	facility for all island transportation access for clients more trainings for providers own lab – quicker turn around for results more CTR more linkage with private providers

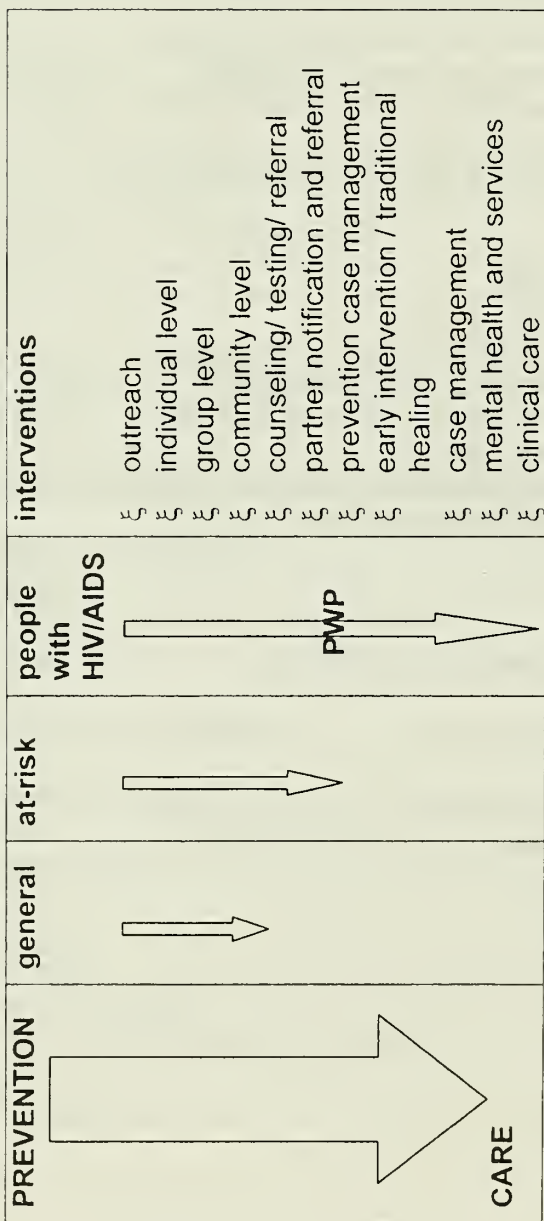
**GUAM**

<b>Current</b>	<b>ideal</b>
DOH is doing PCRS, Surveillance, referrals, ADAP lab capacity is not sustainable contract out some prevention services DOH not doing blood work – contract out regional linkage with Chuuk FSM	lab – level II surveillance dept on it's own reinforce safer behaviors prevention with positives / case management all stakeholders to work on stigma – coordinate with community

**OVERALL THEMES:**

- ξ need for infrastructure building
- ξ striving to work more with community stakeholders, CBOs, etc.
- ξ increase training opportunities
- ξ access to medication (current – need to improve)
- ξ need for lab work / lab facilities
- ξ need for referrals (mental health, partner notification, etc.) for PLWHA
- ξ CTR and community level outreach as main prevention interventions

# HIV/AIDS CONTINUUM OF CARE



JURISDICTION UPDATES (lab related)

Jurisdiction	Lab testing avail?	Type of test	Turn-around time	Sent to	Monthly # of tests	Annual #	Orasure testing	HIV funding	Fax?	Comments
AS	yes	elisa	1-2 weeks	HI	varies	400	no	federal	yes	walk-ins 1 private clinic, hospital-based include blood donors and pre-natal
CNMI	yes	elisa, plus orasure in future	1 week	HI and Kansas	60	600 (30,000 for 5 private clinics)	yes (but problems right now)	federal	yes	90% pre-natal 5% diagnostic 5% HIV/STD clients
FSM Chuuk	yes	determine plus oraquick		CDC	200-300	2356			no	
FSM Kosrae					100				no	
FSM Yap					100				no	
FSM Pohnpei									no	
Guam	yes	elisa, orasure	blood 2 weeks orasure 1 week	HI	150-200	2000-2500	yes	local and federal	yes	
RMI	yes	sepedia blood (rapid)	immediate	HI	200-300		no	local and federal	no	
Palau	yes	determine	immediate	HI, DLS	75-80	900	no	local and federal	no	40% blood donors 40% pre-natal 10% high risk 10% diagnostic



## CBO discussion, role in future, clarity of roles

### *WHAT CBO' s ARE CURRENTLY DOING WORK IN YOUR JURISDICTION?*

#### **Palau:**

Red Cross (Miriam Chin, CPG member)  
Palau Theatre (Dr. Otto and Dilmei)  
Milad'I Dil (Benita CPG member)

#### **American Samoa:**

none - the informal organizations are not stable to conduct activities

#### **Guam:**

Red Cross: train the trainer, HIV 101  
Ayuda Foundation: – HIV training, sub-site for AETC  
GUAHAN Project: – support groups, Tiger POZ, Gingerbread Project, AIDS Walk, World AIDS Day, AIDS Art Response. certified as 501 c(3) in June 2003  
Salvation Army

#### **CNMI:**

Red Cross: starter facts, HIV 101  
Karidat: emergency fund  
Visminda: conference, meetings, donations

#### **RMI:**

WUTI (women united together for Marshalls), looking at health issues such as HIV/AIDS, STD and prenatal care  
Youth to Youth: outreach and education

#### **Chuuk, FSM:**

Catholic Mission: media, radio shows on HIV/AIDS  
Chuuk women's Advisory Council: all women's organizations represented, referrals to DPH

#### **FSM:**

Red Cross: media/ ads, peer education (youth) training  
Women and youth organizations to probably be involved

#### **Discussion – involvement of CBOs:**

- ξ role of CBOs is valuable, services can be contracted to cbos
- ξ can represent other communities that are not currently addressed
- ξ eg GUAHAN has good transgender connections
- ξ Questions/ discussion: would be good to share experiences in regards to contracting out services to ngos
- ξ future topic/parking lot – experience of contracting out services – what are the steps?
- ξ some suggestions: quarterly meetings, forms and reports on activities, etc. common mission, fit both for public health and with ngo
- ξ Guam has contracted out having 10 new MSM test clients
- ξ sole-source issues
- ξ CBOs can be referral/ outreach sources

## LAB strategy/ standardization

*Are the jurisdiction planning to use the lab in Guam?*

American Samoa (ELISA on island and send to HI for confirmatory)  
rest of the jurisdictions (Palau, RMI, FSM, CNMI, FSM) will send to Guam

*Would like to know from Guam:*

what would be the minimum number of test for bulk purchases, etc. – not sure yet, will check with Orasure  
what is the minimum number of tests (specimens sent) expected from each jurisdiction?  
batching – how many specimens need to run test – ask Orasure

*Guam would like to know:*

- what your birth cohort/annual is?
- positivity rate?

*Forms:* everyone is using DLS standard form

*Specimen transport:* PIHOA will be responsible for working out the MOUs

## Friday, October 31, 2003 Care and Treatment

### Goals:

- ξ Examine state of current spectrum of care services
- ξ Identify where jurisdictions want to go, how to get there, and who can help

TIME	CONTENT/ TOPIC	EXPECTATION
9:00 am	Welcome	
9:15 am	Jurisdiction updates related to care/treatment	Information sharing
10:00 am	AETC Update – Jane Waldron presentation Etc Past, Present, Future	Information sharing
10:30 am	ETC collaborations Trainings / Chuuk site / new Guam site	Discussion Decision making
11:00 am	Continuum of Care	Discussion, Determine common areas of training and future discussion topics for workplan
12:00 pm	Lunch	
1:30 pm	AHP review / Regional effects & Core indicators HI presentation – Nancy Kern and Tim Juday	Information sharing
2:30 pm	Care related to the AHP Initiative	Discussion
3:00 pm	Dr. Parham letter follow-up	Evaluate what has been done and what needs o be done, add to workplan
3:30 pm	Standardization Pricing, Access to medication, ADAP-related policies, and treatment regimens	Discussion, Decision making, Create plan and next steps
5:00 pm	Wrap-up and next steps	
5:00 pm	Adjourn	



## CARE AND TREATMENT NEEDS ASSESSMENT

<b>Social Services</b>				
<b>Jurisdiction</b>	<b>Services Available</b>	<b>Challenges</b>	<b>Goals</b>	<b>CBA/NDS</b>
<b><i>American Samoa</i></b>	-Support services by program staff -No housing	-	Have support group for HIV +	Training within local health care system
<b><i>CNMI</i></b>	Housing, food stamps, link with CARIDAT support group	-No support group -Housing, slow to provide	More communication + Linkage with providers	More training for provider
<b><i>FSM</i></b>	None	Limited fund		
<b><i>Guam</i></b>	Gay men + TIGER POZ support group, food stamp, gas + food coupons, nutrition supply + H2O	No building, Limited time and funding	Have office discrete comfortable meeting space Titile III Grant submitted, case management at CHC's	Funding training collaboration with public health + CBO other entities involved to collaboration + get \$
<b><i>Palau</i></b>	Counseling + nutrition	Staff don't have knowledge (HIV specific Issues)	PWH + family have involvement + participation.	Training on multidisciplinary care management
<b><i>RMI</i></b>	Mental health nutrition + social services	Public unaware of what can be offered	Planning process to deliver social services	Hire trained social worker

Prevention with Positives				
Jurisdiction	Services Available	Challenges	Goal	CBA/Needs
<i>AS</i>	F.U. Counseling	-	-	-
<i>CNMI</i>	Counseling for partners	Not enough training	More linkage with positive to offer services to partners i.e. CTR	More training + resources available for partners
<i>FSM</i>	Continuum of care for OI CTR + health education	-Limited staff & skills -Visiting patients -Providing care	Train counselors in all 4 states	More resources for CARE + CTR training
<i>Guam</i>	Limited case management, families take care of patients, - Tiger Poz support group	Limited resources, gaining trust to participate + access services confidentiality + fear of disclosure	Highly skilled staff to provide services to positives -have regular support group + speak PWAs panel	Training for community organization/ volunteers -less governmentt involvement - incentives, funding + office space
<i>Palau</i>	Counseling + partner notification	Privacy issues, partners moving out country	-	-
<i>RMI</i>	No counseling	No trained staff	To implement prevention with positives	Training highly recommended

<b>CTR</b>				
<b>Jurisdiction</b>	<b>Services Available</b>	<b>Challenges</b>	<b>Goals</b>	<b>CBA/NDS</b>
<b>AS</b>	CTR	-confidentiality -Location	Offices PPL would be comf going to	Close collab within jurisdiction
<b>CNMI</b>	-HIV pre/post test counseling outreach/condom distribution -education awareness	-Lack of human resources -referral services -low return rate	-More testing -More staff and FTE's	More CTR trainings provided Hire more FTE's
<b>FSM</b>	-CTR -Outreach	-CTS -Transportation -Short of staff -Inadequate space for privacy	-CTR in place -Confirmation venue identify	-Testing method training -2 more CTR staff -Adequate CTR space
<b>GUAM</b>	-referrals -limited case management -material distribution -GP sessions -CTR (5 P.H. sites)	-Limited staff -No building or infrastructure	-offer CTR in a building/care management services -routine testing in hospital, school, clinics -Doc/superior court education school HIV prevention counselors	-strategic planning -CTR certifice -testing capabilities -technical assistance for training -evaluation of HIV activities
<b>Palau</b>	-CTR	-lab support -privacy	-be able to ship specimens off island (wb, viral load, cd4)	Lab consultant
<b>RMI</b>	-CTR (Majuro & Ebeye Public Health) -CTR outerislands quarterly -health education	-need more CTR trainings	-More alternate testing sites -More trained staff on CTR	Technical assistance from CDC to do local CTR training



ACCESS TO MEDS				
Jurisdiction	Services Available	Challenges	Goals	CBA/NDS
<b>AS</b>	-HIV medications avail	-Delay in getting med order for clients to utilize	-For us to hold meds to distribute from our clinics -Connect with pharmacy company and develop own formula to order meds	
<b>CNMI</b>	-medication counseling -Ryan White Title II available for medications -referral for housing, food, Nutrition	Transportation for HIV + clients to pick up medications	-More access for HIV+ patients to pick up meds	-transporting patients -communicate with patients better
<b>FSM</b>	No access	Lack of funding and no system in place	-funding avail -access to medications -system on purchasing medications	
<b>Guam</b>	-information /link with medication social services & pharmacy -ADAP / private insurance and HAART therapy -MIP/Medicaid	-limited office & clients resource center -public funded insurance faces financial instability -private clinics do not accept MIP/medicaids clients -MIP not cover "trade name drugs"	-purchase medications at lower cost -bulk order adapt TX/prescribing guidelines -further indevelopment care management and CTR services	-AETC playing larger role enhance clinical care TX guidelines -standardize care -collaboration with pharmacies, public health and insurance company
<b>Palau</b>	-medical, Tx -drugs	-cost -timelines of orders	-Mou - explore regional purchase options to lower cost	Not sure
<b>RMI</b>	None	Need technical assistance in linking	HIV medication access	Establish linkage and train staff to use linkage

HIV Case Management				
Jurisdiction	Social Services	Challenges	Goals	CBA/NDS
<u>AS</u>	-Oversee care of cases when they come to hospital	-Lack of stable system of management and experience in HIV management	Standardree system of care	CB providers to provide training, close collaboration b/n DOH & local hospital
<u>CNMI</u>	-Counseling -Referral to other provinces -Food stamps -MI HA	Not enough trained staff only 1 on island	Add all staff for CM	More training for counselors
<u>FSM</u>	-None (FSM National) -Counseling and TX of OI (Chuuk) -Follow upon PAT status	-Limited staff -Limited services and skills	-Case management services in place -Referral nutrition, MH, Med Access, outreach, support services available	-Trainings on CM -Training of counselors
<u>Guam</u>	-Medical/Social services -Community services -Home visits -Hospital visits -Advocacy -Referrals	-Limited resource -Shift of focus to other health areas -Higher health priorities -No \$ / No formal intake process	-CBO Prov ADAN case management funder -Funding More grounded delivery of CM	-Training -Case management models -Funding -Staffing
<u>Palau</u>	-Case management – lacks lab test (CD4, VL)	-Support services not used fully, labs	-Resource specimen transport concerns	-Yearly hazmat training -Supplies for and shipping of specimens
<u>RMI</u>	None	-No one is trained -Program development ND's	-Case management system be implemented	-Train right people in care management

## Hawaii ETC - Jane's Presentation

- ξ HI AETC as a part of the California ETC – the Pacific AIDS ETC
- ξ main goal to train docs, nurses, and other clinicians etc.
- ξ 2000 – HRSA approached Pacific AETC as a group – asked to provide training to the Pacific Islands, came out of PIHOA thru the Dept of Interior
- ξ HI AETC is responsible for training in HI, only in last 3 years – they have expanded into the Pacific, sent teams in each jurisdiction for needs assessments

**Phase I:** HIV Clinician Needs Assessment

**Phase II:** 5-day HIV clinician training event in Guam (Marshalls not able to attend due to Cholera Outbreak)

**Phase III:** Jurisdiction Specific HIV Care Consultation (May – June 2001)

**Phase IV:** Off Island Physician and Nurse Miniresidencies (July – Dec 2001) HI & CA

**Phase V:** Second 5 Day HIV Clinical Training Event (April 2002) Honolulu

**Phase VI:** Ongoing distance based learning Clinical Consults began July 2002 (via PSAT)

Site Visit: put resources out in the region for local level training: Guam & Palau responded initially to become an LPS via doc's recommendation

Visit with Palau: Vice President, Minister of Health and Dr. Otto, Dr. Dever etc. –  
one center will not serve the region  
why not in Chuuk?  
why did AETC not speak to the "higher ups"?

Site visit to Guam: University of Guam, Ayuda Foundation etc

**Phase VII:** Development of first Hawaii AETC subsite in Pacific

January 1, 2003 first site in Chuuk

incorporating Pohnpei and Kosrae in the coming year  
conference with FSM and RMI 2-3 day clinical training

**Phase VIII:** Third Clinical Training Conference in Hawaii April 2003

**Phase IX:** Development of the Second Hawaii AETC Sub-site in the Pacific Sept 2003

Guam sub-site in Ayuda Foundation with part-time Training Coordinator  
Plan to expand scope to include CNMI, Palau and Yap(?)

### **The Future:**

- ξ internet access
- ξ support regional centers
- ξ collaborate with PBMA directors of health
- ξ Provide education training resources
- ξ support consultation and referral (Amy Kindrick, MD, MPH); regional experts

### **Recommendations:**

- ξ APLNA has not responded as readily and the physician group – AETC should review this strategy is the recommendation from PIJAAG (Hana)



- ξ Develop a directory across the region of HIV clinician experts and support systems
- ξ Develop and support a mechanism for bulk purchasing for medications
- ξ Amy Kindrick would be good to pull into this conversation and is a complex process since medical regimens are not universal accepted by patients across the board

#### **Questions:**

1. How do you integrate with HRSA about your activities in the region?  
via Michael Reyes as the PAETC director
2. What about purchasing meds from India or Australia?
  - a. allowable in some places – yes we could explore
3. What about genotyping? There is very little capacity for this in the region.
4. How can we support the training needs in public health and medical communities?
  - a. not sure; try to have some from both acute and chronic side
  - b. have tried to get both sides involved and the regional sub-sites
  - c. cycle of funding: 3 year cycles for 15 years ; we are trying to get most of the \$ out to the Pacific ; we won't be able to get more \$ due to flat funding
5. Location in American Samoa – how will effort be expanded or sustained here?
  - a. via PSAT
  - b. please think of something that is low resource and supportive
6. How do we propose a training idea to AETC?
  - a. i.e. lab report interpretation etc.
  - b. we can integrate this into
7. Can we get access to training calendar?
  - a. via the CBA point person or email list – via Pacific e-listserv
8. list of training participants per training attended

#### **Guam Site Update: started Sept. 2003**

- ξ training of doctors
- ξ Amy Kindrick coming January 2003
- ξ working with social workers and social work students, lab techs

#### **Chuuk Site Update:**

- ξ change of director of health twice
- ξ relationship with docs is good
- ξ Presentation to 50 nurses, with CEU's and goodies
- ξ included: epidemiology, HIV 101, risk assessment, P&P of CTR, clinical manifestations of HIV/AIDS, clinical management
- ξ Presentation to 70 to health workers
- ξ Future: Kosrae will be future training sites

#### **Training Needs for the Future:**

AS: lab results interpretation around indeterminants of positivity

CNMI: meds assessability

case management  
support group for HIV+

FSM: CTR  
effective counseling  
case management  
program planning within states/ and across

Guam: clinicians that can train other clinicians on medical care & treatment, esp. in  
community health centers  
case management  
cultural competency capacity building around outreach and access to ctr

Palau: HIV training for social workers  
Annual hazmat training

RMI: CTR  
case management  
HIV training for social workers

### **Regional Training Needs**

- ξ treatment advocacy
- ξ drug regimens for resource in poor areas
- ξ co-morbidities
- ξ allied health professional training
- ξ collaboration training between DOH and hospitals/medical providers
- ξ inter-island relocation of HIV client and transition
- ξ partner information and follow up

### **AETC has thus far, conducted training on:**

pregnancy, nutrition, perinatal, risk assessments, ctr, handling dead bodies, oi,  
alternative to labs, confidentiality, advocacy, spirituality, resistance, internet resource,  
systems- public health model, grant writing, terminal care, med updates, social issues,

## AHP Review Regional Effects and Core Indicators

Tim Juday (UOH) & Nancy Kern from DPH, HIV/STD Hawaii joined us for the afternoon

### **Performance Indicators**

CDC is creating Performance indicators

#### **pluses**

- ξ planning goals and be able to assess long term plan along the way
- ξ 9 core indicators for the PIJ

#### **cons**

- ξ many of these indicators have been developed for large prevalence areas, not small prevalence areas
- ξ Pacific will have nine to respond to but fitting into the box can be difficult
- ξ In HI, hard to fit into the box and we are responding the BEST we can based on the best information we have.—use the framework of the performance indicators
- ξ use qualitative measures in place where hard numbers are not avail.

#### **Indicators that were problematic for HI:**

A1: number of newly diagnosed HIV infections (HI doesn't have published HIV data only AIDS) can say do not have this and put AIDS data or insert what you will do what

A2. Proportion of HIV/AIDS cases of total infections—take the best quality data and use it.

H2. mean number of contact required for any individual to access the following services: std testing etc.

- measurement issues are difficult—count outreach contacts, ctr, referrals, group interventions and looked at trend data and then created a proportion
- this will be experiential, best guess—not very scientific

Guessing trends in one year and five years are very difficult but we will be able to revise over the years

Perinatal HIV screening –low numbers and CDC is willing to work something out with these low prevalence jurisdictions to shift priorities. Some of these indicators also raise questions about resource use.

B1. Testing: separating out never testors vs. retestors who were already HIV+

PCRS: HI doing long range planning on PCRS. Performance indicators have helped some of our thinking around this.

There is room for negotiation around these performance indicators because they are poorly developed. They may help focus your programs more.

Formulate your own goals.



## Nancy Kern presentation on AHP in HI

HI : two reactions:

- weren't overly concerned because we were on top of it
- concerned about how AHP was going to have an impact on total HIV prevention programs
- HI low impact state

Routine testing in medical settings: was important but would not affect current contracts too much, DOH to work with HI AMA

Perinatal: low numbers among pregnant women; have been working with private MDs to counsel women to test encourage women to test during pregnancy with pamphlets 15,000 live births & 85% offered an HIV test

CTR/PWP: These interventions were already prioritized in HI CGP. Interventions with PWP required development and a coordinator was hired to develop. PCM in Honolulu is provided. In neighbor islands, it is more difficult to sustain this.

Rapid testing: Lab branch is having a difficult time adopting to CLIA. (lab tech needs to be there to interpret the test in HI) Orasure testing has worked very well in rural areas.

CPG and DOH partnership has been invaluable to get here.

Design of P4P interventions:

- needs assessment conducted first- what are their prevention needs?
- recommendations were developed from this and CPG and an RFP was released.

\*\*\*For health departments, there is an emphasis on AHP and continued HERR will be allowable from CDC funds from high risk negatives and continue to adhere to local CPG.

## Discussion on AHP Impact Presentation:

What about CPG members involvement in AHP implementation?

- consultation will kick-off the development in Guam and then each jurisdiction will have a year to develop a plan.
- training for coordinators on AHP in FSM
- even if no cases, have plan in place
- document behaviors that create risk and testing—large migrant population

### Dr. Parham's Letter/HRSA follow-up

Delayed f/u because of project officer change at HRSA and Vince's departure but we have made significant in-roads on care issues.

We want to ensure a target follow up letter with Dr. Parham by the end of this discussion and review the letter today.

Prescott reviewed the timeline of meeting with Dr. Parham. HRSA supported the PIJAAG conference with about \$15,000.

Who is the equivalent of Vicky in HRSA?:

Karen Invelstag is the new HRSA project officer for the Pacific.

**\*\*No travel budget for her: Include in the letter annual site visit to PIJ**

**need clarity on Gor Yee's role, if any**

**Joanne Spearmon—ADAP**

What are our next steps?

- ξ **LETTER (FOLLOW UP FROM DC MEETING): can have a follow-up meet at next all titles**
- ξ Letter should talk about what PIJAAG is doing even without the additional resources – highlight situation today
- ξ HRSA should help figure out bulk ordering
- ξ Letter should talk about accomplishments and really figure out what they can't do without further resources from HRSA.
- ξ standardization of care in resource constrained regions
- ξ update on lab, transportation, training in the region/AETC
- ξ case vignettes on situation today in the Pacific
- ξ Clinical outcomes
- ξ include adap issues for PIJ that don't have it (i.e. fsm-chuuk)
- ⌚ **conference call: with Ginny Bourassa & Karen Inglesod at HRSA on updates both ways (priority) Prescott and Lina will set up**
- ⌚ follow up meeting with HRSA at all titles mtg (find out meeting date)
- ⌚ **follow up with AETC in identifying training needs (priority) ManChui and Javid will follow up**

## Standardization Across Pacific Island Jurisdiction

### **Pricing**

- CVS (Guam), Amerisource (Guam), Med Pharm (Guam, Palau) – check to negotiate prices
- some have problems with credit with Peripoint
- AS and CNMI order through pharmacy (Tony Roho/ pharmacist on CNMI has been helpful – can use as contact/resource)

Recommendation: meet with reps to see if bulk purchase is possible

Recommendation: meet with Pharm reps to figure out their formularies for bulk purchasing

### **Access to Meds**

- Karen (HRSA) stated that you would be able to use Title II funds to purchase meds from international vendors (advised to double check).
- cost ability to get drugs on island on time
- deal with procurement problems
- returning unused medications? possible?
- consistency of care and prescription issues
- FSM not able to access HAART meds—set up through CVS in Hawaii
  - create compassion programs with pharmacies (Bernie)

### **ADAP-related policies (Guam, CNMI, RMI)**

- to get drug formularies- reassess what is included based on avail\$
- check in with Rob to take the lead on this

### **treatment regimes**

- AETC to take lead

**For Future Next Steps:** Advocacy orientation & Media strategy to increase access to medication for the region.



Thursday, October 30, 2003

CDC Program Announcement and Application

Goals:

- ξ Assist in developing application to CDC
- ξ Clarify and answer questions/ concerns
- ξ Identify next steps

TIME	CONTENT/ TOPIC	EXPECTATION
9:00 am	Welcome	
9:15 am	CDC Update of Program Announcement and Review	Information sharing
10:30 am	Program Announcement section by section Worksheet and performance indicators	Discussion
12:00 pm	Lunch	
1:30 pm	Program Announcement section by section con't	Discussion
3:00 pm	CPG – making a new model for the Pacific	Discussion and decision making
3:30 pm	CDC Consultation in Guam	Discussion and decision making
4:30 pm	Wrap-up, Next Steps and Closing	
5:00 pm	Adjourn	

**Overview of the Program Announcement**

- ξ Starting plans – these plans will be for the next 5 years of the program
- ξ Working in teams to plan
- ξ checklist of what is needed in your plans
- ξ application for the funds to continue for the next 5 years
- ξ road map to do your application
- ξ Program Announcement 04069
- ξ still not finalized (going through clearance)
- ξ will be out in the next couple of weeks
- ξ **due January 27, 2004**
  
- ξ Vicky reviews new areas: line 32, 71, 77, 83, 89,
- ξ -avail of total \$-level funding for all jurisdictions—stay consistent for 2004

**Overview of Core Indicators**

- ξ notebook – technical guidelines to the core indicators
- ξ Pacific has 9 indicators / everyone else – 20 indicators
- ξ background of core indicators, overview also good to read
- ξ forms included and suggested, but not mandatory (currently not cleared through OMB)
- ξ some indicators may not apply – in this case, jurisdictions should document what the situation is. this can be used as baseline data for the jurisdiction plans.
- ξ can contact Romel Lacson on conference call if there are questions on the core indicators.

**Program requirements which will be our key focus today**

- § some requirements may not be as developed and this is okay
- § these requirements are not optional, but can be geared up with CBA, CDC support, more time etc.

**SECTION by SECTION:**

Line 124a: CPG—will embark on developing a CPG model in this next year

Line 178-Dunns Number required

AS, FSM, RMI, CNMI and Guam are awaiting. Palau has one.

\*\*\*Vicky to support AS, & RMI (Follow up)

Line 216: can discuss the challenges, etc. state where you are at. assumption is that you can do all of this today. this is a chance to state clearly where you are at.

**REMINDER: you are applying for a 5 year project period. You need to also project where you want to be in 5 years. Budget, however, is only for this first year. If you don't have numbers, use words to paint the picture.**

Line 224: community planning model specific to the Pacific. There is an opportunity for grantees will work with CDC to create new, appropriate model

Line 250-255: involvement of community in planning. year 1 development opportunity. the consultation in December is the kick-off for this development period.

*question: can CBO be contracted to do logistics for CPG?*

*answer: need to first go back to the development of the model.*

*look at the values of community planning: partnership, involvement of community and community stakeholders most at-risk*

Sections A1 and A2:

- § won't be penalized if numbers not met
- § jurisdictions need to be able to analyze, document, and defend results
- § unique identifier systems vs confidential systems (HIV reporting)
- § for A1 and A2, surveillance data, if not available, write narrative
- § try for a number
- § for newly diagnosed individuals, need to look at at-risk populations
- § also identify challenges

*Question: what is happening with HRSA, given the new infections possibly to be identified? lack of resources, etc*

*Answer: NASTAD had put out a paper with criticism, but no resolutions have been decided*

*CDC needs to take leadership to coordinate with HRSA, etc*

Requirements of CTR: must do CTR in the following items. Line 314 – 328 tells you what you need to incorporate in CTR for application

- establish or improve identifying new infections
- provide test results
- expand CTR availability
- referral plan / tracking
- prevention / risk reductions for high-risk negatives
- work in medical care entities to support routine HIV screening

Line 264 – 269 should be collecting data on basic demographics for publicly funded programs

\* post-test returns important to report

**REMINDER:** core indicators are asking for numbers, but if you don't have it, give narrative

**REMINDER:** can use the information from Day 2 (homework and care and prevention matrix) to do the application

HERR need to:

- target people most at risk for HIV
- based in science, replicatable, protocols and procedures in place
- how are you going to get some of these activities out into the community?
- list out priority populations
- don't have to use community planning prioritization right now to describe here.

Line 692 Quality Assurance

must have quality assurance in every activity  
mechanisms for oversight and documentation  
training needs, sampling, etc

*Comment: currently using 5 questionnaires (client satisfaction surveys). These are good example for the jurisdictions to use.*

Public Information campaigns

- no core indicator needed right now
- narrative only
- need to provide rationale on approach
- complete this section if you are planning to utilize and budget for public information

*question: evaluation mechanism? how do we measure?*

*Answer: can ask clients as they come in how they heard about the program, etc good to do on a regular basis*

Perinatal - last section with a core indicator

- universal safety net – perinatal transmission can be greatly reduced
- look at the MMWR guidelines for perinatal
- work with agencies that are providing perinatal care
- working towards a 100% strategy



## Evaluation

CDC transitioning to PEMS (Program Evaluation Measuring System) a web-based reporting system

## Collaboration and Coordination

Line 582 – 584

- can use \$ for STD treatment (when approved by CDC)

*question: can AZT treatment to prevent perinatal transmission be supported through CDC?*

*answer: maybe – will need to check*

collaboration could include another regional summit

## Lab support

- utilize information from the lab discussion
- needs to be in the application
- some lab requirements
- describe regional lab usage, etc

Line 667 Core HIV/AIDS epi and behavioral surveillance

- any money for surveillance, list here
- if you are going to go for surveillance dollars, state this

Line 799 Capacity building

- capacity that is not already mentioned under any of the other areas
- broad range that can be pursued – trainings, consultants, etc
- side discussion with Rob Janssen re capacity building resources for the Pacific
- jurisdictions should list out needs even though there are no identified resources – use as an advocacy approach
- if PIJAAG is planning to do a conference in this next year, it needs to be in the capacity building section here.

*Fara's inspirational mantra:*

*ManChui – Macho to complete this application*

*Lina – Line up your activities*

*Prescott – Press On*

*Javid – Joyous*

*Xuan-Lan – Soothing*

*Vicky – Victorious*

## COMMUNITY INVOLVEMENT/ COMMUNITY PLANNING IN THE PACIFIC

### Community Planning

what works	what doesn't work
quarterly meetings / on a 2-3 year plan	member retention difficult to focus each month on the plan (Guam)
give CPG more opportunities to do other things (eg outreach, etc)	people not interested in attending meetings anymore (Guam)
long-term participation works if also working with program	long-term participation doesn't work
planners work for public health	need people that can give ideas, but hard for community – no initiative
focus groups (shorter time, specific)	in the past, the jurisdictions have been independent. but because of colonization, people are dependent on the ministries. make the people dependent on the infrastructure, etc
involvement of informal at-risk groups (like gays, etc) via program activities, cpgs or focus groups	difficult to involve the local community and still get what you need done
lunch for every meeting	need to get more stakeholders / reason to be involved – funding of CPG representative's agencies other concern
introductory packet with roles, etc	culturally, help is not asked for directly (not dignified) if someone needs help, it should be offered and it is the community's responsibility. therefore, having HIV+ people on CPGs to advocate for HIV+ would be problematic. eg food baskets for elderly – problem with families (felt that it was disrespectful)
forum has created dialogue that wouldn't have happened otherwise	consent forms – difficult – doesn't know what consent means – leery about intent.
	HIV+ folks didn't see need to be on prevention, since they are already infected
	aggressive members on CPGs. all want to go on the trip
	member retention and selection – only HD people end up showing, only higher up people were chosen

## CDC Consultation on December 11 – 12, 2003 in Guam

Who is coming:

jurisdictions 2 to 3 people (PIJAAG, plus staff)

Dr. Janssen

Matt McCraw

Vicky Rayle

CBA providers

maybe Hawai'i

maybe Karen from HRSA

maybe Tom Cylar from STD

maybe Romel Lacson from PERB

This meeting first meeting with CDC and its grantees (HD)

### GOAL OF CONSULTATION

- dialogue about current situation
- update on shift in approach

### POSSIBLE MODELS TO REMEMBER

- community advisory boards

### QUESTIONS

- what are the activities that have to remain? goals and process

### NEXT STEPS

- names of participants
- agenda preparation
- HD meet with CPGs to discuss the current situation
- potentially full meeting with HD and CPG members in 6 mos.

Jurisdictions should also look at their own vision of its comprehensive HIV program and how communities will be involve and will help with community involvement



## **ANNOUNCEMENTS / OTHER BUSINESS**

### **Surveillance Announcement PA 04017**

out, due January 16 in Atlanta  
only eligible for core surveillance  
no more than 15 pages  
Vicky will cut the Pacific section into 1 document

### **STD info**

STD starting new project period in 2005  
by November 7, other comments on meeting notes and current STD program announcement

## **NEXT STEPS – WHO'S RESPONSIBLE**

- ξ followup with AETC - ManChui and Javid
- ξ Follow up with Hawaii AETC – Xuan-Lan
- ξ Conference call with HRSA Ginny, Karen – Prescott and Lina
- ξ Letter to HRSA – Josie and Xuan-Lan
- ξ Rapid test training in Hawai'i – Vicky
- ξ All jurisdictions need to get names for consultation to Vicky by November 7
- ξ Vicky will get back to everyone with agenda and letter of invitation
- ξ All jurisdiction should respond to Tom Cylar by Nov 7
- ξ Next PIJAAG Summit in American Samoa in 2005
- ξ AETC to take lead on treatments, etc

### **Request TO PATC (SF)**

- ξ Get list of docs for treatments/ meds, etc
- ξ Treatment regimens
- ξ Bulk buying: what would be the best strategy?
- ξ Pricing: meet with reps from the following companies (CVS, Americsource, Med Pharm, or other "compassion" programs) to see if bulk purchase
- ξ Another option: to bulk buy with Hawai'i
- ξ Questions/ issues:
  - ξ cost
  - ξ ability to get drugs in a timely manner
  - ξ deal with procurement problems
  - ξ policy on returning unused meds
  - ξ Treatment regimens

### **Specifically for Hawaii AETC:**

- ξ get PIJAAG meeting presentation from Jane
- ξ get cards of regimens from Talita
- ξ get list of clinicians who attended trainings/ certified
- ξ review common and specific training needs (day 2) and coordinate with Jane

## **ADJOURN**

